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“You have to find a caring man, like your father!” gendering sickle cell and refashioning women's moral boundaries in Sierra Leone

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ABSTRACT

Most research on sickle cell disorders has tended to be gender-blind. This qualitative study undertaken in 2018, explores if and how sickle cell disorders become gendered in Sierra Leone through the analytical framework of a feminist ethics of care. It argues that women have to navigate moral blame when they have children with the condition. At the same time women refashion moral boundaries so that gendered norms around childhood and parenting for such children become suspended, in favour of creation of careful spaces. Parental fears of physical and sexual violence mean that gendered sexual norms are enforced for teenage boys as they are encouraged into early adulthood. In contrast, girls are kept in enforced ignorance about the consequences of sickle cell for reproduction and are encouraged to delay motherhood. This is because, as women relate, relationships and giving birth are fraught with embodied dangers and risks of violence.

1. Introduction

“Sickle cell is a gender issue, it affects men and women differently,” specified Mrs. Amelia Gabba who was responsible for the day to day management of a non-governmental organisation (NGO) called the Sierra Leone Sickle Cell Disease Society (SLSCDS). It was March 2017 and we had been undertaking a small project in the capital city of Freetown to adapt school policies for children with sickle cell disorders (SCD). This was in keeping with United Nations (UN) Sustainable Development Goals and British aid priorities for a low-income country correlated to children's rights, girls' rights to education and inclusion of children with disabilities. The work we were doing was based on previous SCD research conducted in schools in Britain (See [Dyson et al., 2010](#)), while also learning from experiences of local sickle cell school clubs that had been created with varying success. The NGO was also supported by Sierra Leoneans working in the diaspora who brought with them the latest scientific knowledge, medical language and resources. They supported prioritisation of SCD as neglected public health issue ([Ware, 2013](#)) with a strong focus on understanding prevalence, improving medical care and ensuring prevention ([Roberts et al., 2015](#)). Our work was not regarded as particularly important by medical professionals, politicians nor policy makers, although they were supportive.

However, Amelia was a nurse and a mother who had lost a child with SCD. She viewed outreach to schools as part of ‘awareness raising’ and ‘sensitisation’ in a society where SCD was still stigmatised and signs of the illness often misunderstood, for example, as linked to witchcraft ([Shaw, 2002](#); [Schneider, 2017](#)). In a resource-poor setting, with limited medical facilities, health care professionals like herself emphasised the need for parents to understand how to ‘care for’ their children with SCD to improve life outcomes. In Sierra Leone, this also meant a need to educate extended families, local communities and schools about needs of children with SCD, so they could learn to ‘care about’ them. While there seemed to be an institutional, political and social silence linked to SCD, Amelia understood care-giving as an activity located within public and private realms. In every school we visited, to learn about inclusive policies and sickle cell clubs, there were children with SCD attending. Yet, it seemed as if the way in which SCD was affecting girls and boys was different, despite the same emphasis on care to ensure wellbeing. Why were girls and boys having such different experiences of growing up with SCD?

While her positionality as mother and status of children with SCD to be cared ‘for’ privately and ‘about’ publicly was at stake, so was the term ‘gender’ that Amelia used. Following a ten-year civil war (1991–2001) in the country, the UN and other institutional agencies and NGOs had an operational legacy focused on rebuilding the nation

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state. One of the consequences of the civil war had been gender-based violence targeting girls and women. As such, post-conflict, 'gender' became a programmatic term, a global funding focus, as well as local civil society priority to combat inequalities and advocate human rights (Denney and Fofana Ibrahim, 2012; Schneider, 2019). In a post-colonial country with several sets of laws; customary, legal and Muslim that remained unchanged since the country's independence in 1961, three 'Gender Justice Laws' (2007–2009) were enacted post conflict: the Domestic Violence Act; the Devolution of Estates Act; and the Registration of Customary Marriage and Divorce Act. In 2012, the Sexual Violence Act was also passed to address gender-based violence.

Post-Ebola (2014–2016) there was a renewed focus on gender relations, with a rise in sexual violence and a (now overturned) government ban on pregnant girls from attending school. After huge outcries from civil society and women's organisations, in 2019 the country's president, Julius Maada Bio, declared a 'National Emergency on Rape and Sexual Violence' and an amended Sexual Offences Act was passed. The programmatic term 'gender' thus denotes such past and present experiences of physical and structural forms of violence but also women's advocacy. By using the term 'gender', Amelia was referring to the importance of women's sociality within public and private spheres. Just as gender relations are characterised by what Sierra Leoneans term 'selfishness' or 'carelessness' (Rogers, 2016), concepts exemplified in intimate partner violence (Schneider, 2019), they are also characterised by care-giving. When we spoke to Mrs. Sia Evelyn Nyandemo, a mother of a child with SCD working in the east of the country for an NGO, she agreed with Amelia that there needed to be a focus on gender.

This paper investigates if and how SCD becomes gendered in Sierra Leone through the analytical framework of a feminist ethics of care. It begins by explaining why motherhood becomes connected to morality. Then it explains how gendered norms become morally suspended in favour of creating, what we term, careful spaces. This changes as children grow up and gendered norms become enforced for teenage boys, as they are encouraged into early adulthood and social reproduction, while the opposite happens for girls. This is because, as women with SCD relate, relationships and giving birth are fraught with embodied risks and possibilities of violence.

2. Background

SCD are autosomal recessively inherited blood disorders that affect millions of people worldwide, with around 300,000 children born each year (Piel et al., 2013, 2017). Most of these births are located in Sub-Saharan Africa (Kato et al., 2018), making SCD one of the main chronic health conditions in West and Central Africa (Dyson, 2019). Despite one in four people estimated to carry the genetic trait (a gene carrier) for SCD in West Africa, SCD have been relatively neglected in public health (WHO, 2010) and social science research in Africa, especially in West Africa (see Fulwilley, 2011; Dennis-Antwi et al., 2011; Ola et al., 2016). Similarly, public health tends to focus on 'burden' of 'disease' and impact of 'disability-adjusted-life-years' for countries affected (Weatherall, 2010; Piel et al., 2013, 2017). Clinical accounts also underscore the complexity of the conditions and importance of care to prevent disabling symptoms.

In SCD, the haemoglobin crystalizes and the shape of the red blood cells changes and forms sickle-like shapes, causing symptoms of SCD such as pain, organ damage and anaemia. SCD is variable and while in one person it can manifest as acute and life-threatening, in another it is a manageable long-term chronic condition. Many of the signs of the condition are not visible, such as pain or fatigue caused by anaemia, and, as such, the condition can be understood as an invisible disability. Dyson (2019: 38–45) outlines influences that play a role in how the condition is experienced: environmental factors (e.g. malaria, extremes in temperature, high altitudes); physiological factors (e.g. dehydration, nutrition, stress); social factors (e.g. levels of poverty and healthcare systems based on fee payments) and the interaction with the genetic

variant that a person has. There are several variants of SCD with the most common being termed HbSS and the milder version HbSC (Weatherall, 2010).

Sierra Leone is affected by SCD, with an estimated 3000 infants born each year, that is, approximately 1.3% of all new-borns in Sierra Leone (Roberts et al., 2015). Other estimates state that 19 in 1000 births will have a major haemoglobinopathy (WHO, 2019) and that around a fourth of the population carries a variant of the sickle cell gene but this differs by ethnic group (Knox-Macaulay, 1983), and there are reported differences between rural and urban settings (Roberts et al., 2015). In a 2013 survey to comprehend high levels of anaemia, conducted prior to the Ebola outbreak, Wirth et al. (2018) noted a combined prevalence for sickle cell trait and SCD in children of 21%. When investigating the same prevalence in adult women, it dropped to 9.4% which they stated was similar to 10% estimates by Wellems and Fairhurst (2005). In line with Dyson (2019: 146–147), this might be indicative of large numbers of children with SCD dying before they reach adulthood. Notwithstanding sustained health system strengthening, better nutrition and a free health care initiative, maternal and infant mortality rates remain amongst the highest in the world (WHO, 2015, 2018). According to the World Health Organisation (WHO) (2018:13) there is a, "1 in 7 life-time risk of dying due to pregnancy or childbirth, and maternal deaths account for 36% of all deaths among women aged 15–49." Under-five mortality rates, while still high, have fallen since the country's ten-year civil war but post-Ebola the health care system is still rebuilding, and the COVID-19 pandemic means increased risks for women and children who have underlying conditions like SCD (WHO, 2006, 2018).

Although the WHO (2006) has declared SCD a public health priority in West Africa, there are often no national statistics, screening policies or reliable diagnostic testing methods. A lack of diagnosis can entail early death of an infant with SCD, or repeated visits to a medical centre with extra care-giving and social recriminations particularly affecting women (Hill, 1994; Dennis-Antwi et al., 2011; Fulwilley, 2011). If SCD is diagnosed, health care professionals will usually engage with the mothers in two ways. First, to explain the condition of the child and advise on early intervention, available treatment and importance of care at home. Second, to explain basic genetic information to the mother and chance of having another child with SCD (Atkin et al., 2015; Ross, 2015a). The mother has to be told she has SCD trait and if the father of the child is also carrying the SCD trait, that there is a one in four chance, in each and every pregnancy, that she will have another child with SCD. To ensure informed decision-making for the mother, if prenatal testing and termination is a possibility, the father will usually be invited for a blood test to understand if he is a carrier too (Atkin et al., 2015).

In countries where healthcare is not free and there are limited therapies available, the costs of medical care have to be paid by the family. Women as care-givers are affected, as they bear responsibilities of everyday care, as well as working in the (in)formal economy to supplement costs of treatment (Hill, 1994; Fulwilley, 2011). Mothers also have very real fears about how best to care for a child with SCD and if they will reach adulthood, with common societal discourses stating people with SCD will die before age eighteen (Dennis-Antwi et al., 2011; Ola et al., 2016). How people navigate such structural violence to raise children with SCD is different, and thus Hill and Zimmerman (1995) found that in the context of the United States (US), girls are viewed as 'valiant' and boys 'vulnerable'. Less is known about how women with SCD, once they reach adulthood, further negotiate marriage and reproduction (Fulwilley, 2011; Ross, 2015a,b). In order to investigate such issues, we decided to use a feminist ethics of care.

3. A feminist ethics of care

Empirical research in Sierra Leone about women has been linked to post-conflict and post-Ebola state rebuilding, for instance, tackling health, justice and sexual violence (Denney and Fofana Ibrahim, 2012;

Schneider, 2019). However, little has been written on care or even love within the family setting linked to disability or chronic illnesses (Szántó, 2019). A focus on justice and rights in the public realm also lies in juxtaposition to the manner in which key informants, like Amelia and Sia, take seriously a moral 'injunction to care' (Gilligan, 1982). The emphasis on 'gender' to understand differing caring trajectories for boys and girls is reminiscent of Gilligan's (1982) work, taking seriously women's moral reasoning. While an ethics of care has often focused on motherhood (Ruddick, 1989), for example linked to disability (Kittay, 2011), we examine care as wider political concept for an African setting (McKenzie, 2016). The inclusion of the word 'feminist' entails a questioning of how care becomes implicated in relationships between genders and associated, in particular, with the oppression of women (Fisher and Tronto, 1990).

Such a framework is found in the work of Tronto (1993, 2013) who argued it was critical to understand morality within a wider political context (and power relations) to explain why care becomes disproportionately framed as women's work and consequently socially devalued. In the geopolitical West, Tronto (1993) argues that there are three boundaries that typically shape the way in which we understand morality as unconnected to democracy and citizenship. First, morality is seen as separate from politics, secondly, moral arguments are made from a detached point of view and lastly, morality belongs to public and not private life – each of these three aspects side-lines women's 'morality' (Tronto, 1993: 6–10). However, to take the private and personal seriously, is to understand 'care' as 'a practice' that exists in a specific historical and cultural context, in which in each phase of care needs 'ability factors' (e.g. 'time, material resources, knowledge and skills'). When these ability factors are unbalanced, they cause tensions and mean care can become destructive (Fisher and Tronto, 1990: 41). Care is broadly defined as:

“... a species activity that includes everything that we can do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment” (Fisher and Tronto, 1996:40).

This is an all-encompassing definition of, “caring that crosscuts the antitheses between public and private, rights and duties, love and labour.” (Fisher and Tronto, 1990:56). According to Tronto (1993, 2013) there are five phases of care: 'caring about'; 'caring for'; 'caregiving', 'care-receiving' and 'caring with' which are not consequential, can occur simultaneously or one without the other and may also arise in conflict with one another. In Fisher and Tronto (1990), the first phase involves an 'orientation' towards 'selecting' or choosing what activities are going to be needed maintain and repair our world to 'care about', while the second implies a 'responsibility for initiating and maintaining' those caring activities. These tend to be viewed as higher order activities occurring at community, bureaucratic or institutional levels. The third phase incorporates how the day-to-day task of caregiving is undertaken by a person, and the fourth phase is about the responses of the care-receiver to care-giving, inclusive of judging and becoming responsible for it themselves. These last two phases tend to occur in community, kinship and family relationships, where although women may seemingly have more power, care can be interpreted to encompass the duties of traditional values and practices. The example Fisher and Tronto (1990: 50) give is that good care may be interpreted as 'physical punishment of children'. The fifth phase is when patterns of care or habits emerge over time in a community, society or bureaucracy (Tronto, 2013).

The five phases can also be translated into ethical elements of care: 1) attentiveness; 2) responsibility; 3) competence; 4) compassion; and 5) trust and solidarity (Tronto, 1993, 2013). The phases of care with their ethical elements can also reveal practices that would encompass carelessness (Rogers, 2016) or uncaring behaviours. Rogers (2016: 90) argues that, 'Emotional, practical and socio-political spaces' which should be caring become 'care-less spaces' and thus dehumanising.

Applying a framework of a feminist ethics of care clarifies why mothers become moral actors and how moral boundaries are structured in a society. However, first we turn to how care structured our methods and methodology.

4. Methodology

The project used qualitative methods to explore how SCD impacted on women as intergenerational care-givers of children with SCD, in their mothering roles and/or as women who had SCD (Berghs et al., 2019). Ethical approvals were given by De Montfort University's Health and Life Sciences Ethics Governance Committee and semi-structured interviews took place in May and June 2018. We worked in partnership with SLSCDS located in the urban capital of Freetown and the Sickle Cell Carers Awareness Network (SCCAN) in the more rural town of Koidu in the east of the country, that were headed by Amelia and Sia respectively. At the start of the project we discussed possible ethical issues that could occur, the importance of confidentiality and protecting the identities of the women who took part (Bryman, 2015). The two organisations and their staff were paid for the work on the research project. They were responsible for recruitment and sharing of both oral and written information about the research project among their members. They noted how participation would be confidential and voluntary but also inform their services about women's issues and contribute to local and global education on SCD.

5. Semi-structured interviews

In keeping with participatory design of the project, we discussed aims with members of the NGOs and agreed that the project would employ semi-structured interviews (Bryman, 2015), which would allow key informants to follow a guide, aid comparisons between interviews but also allow flexibility for interviewees' responses. Then we undertook a close reading of existing literature on SCD and women to inform questions to guide these interviews and checked with our key collaborators for cultural sensitivity. The questionnaire was the same for all women involved but was amended slightly if we were interviewing women with SCD or/and caregivers of children with SCD.

We adhered to social science research principles but also wanted the interviews to be grounded in ethics of care towards our participants (Hammersley and Traianou, 2014). We wanted them to feel comfortable to share their stories as women in a participatory 'caring' group setting but also ethically supported in case counselling was needed afterwards. As such, we felt that it was important that Amelia and Sia who, in practice, were leading the NGOs and had a background in counselling, take the lead in the interviews. This was also because we wanted the interviews to take place in the lingua franca, Krio, and with people that participants trusted. A foreign researcher was present in a secondary role to act as support, check sampling and ask follow-up questions. The interviews were also held at the voluntary sector premises where women's questions or counselling could be followed up by staff, if the participant gave permission. If women became upset during an interview, we agreed we would stop the interview and give support. In practice, while women did get emotional during interviews, inclusive of the interviewers, most asked to continue with interviews after we suggested to stop.

Similarly, while participation in the project was voluntary and we did not reveal a small payment would be made after the interview, along with transport fees if needed, more women wanted to do interviews than we had originally anticipated and we had to turn participants away. A total of 36 women agreed to take part and share their experiences of what it was like as woman living with SCD and/or caring for children with SCD. We discussed selective sampling needs with the two NGOs responsible for recruitment and in total 18 women in Freetown and 18 women in Koidu agreed to be interviewed. They were all aged 18 and over and living with SCD and/or were caring or had

experience caring for child/ren with SCD, such as in the case of grandmothers. The youngest person with SCD we interviewed was 18 and the oldest was 65. We also sampled for diversity in terms of ethnicity, literacy, impairment, age, family structure and socio-economic status (See Table 1 – where they have all been given pseudonyms).

6. Data management and analysis

After consent had been given, all the interviews were digitally recorded and this data was kept safe on a password-encrypted computer in a locked office. A debriefing was held with NGO staff in Freetown and Koidu to discuss what seemed to be the main themes coming out of the interviews at the end of each day and also overall at the end of the project. Ethics of data management and maintaining confidentiality of the participants was emphasised at each of these meetings. The audio data was transcribed and translated from Krio to English by an independent transcriber and two members of the team. These transcriptions were double-checked by a Sierra Leonean postgraduate with no association with the project team. The interviews were then read by another researcher who had been uninvolved in the interviews to see what they thought main themes had been. This was further checked by coding in NVivo-12 using an adaptive approach, enabling application of theory (Layder, 1998; Bryman, 2015). An adaptive approach (Layder, 1998) meant that as well as checking data in relation to extant theory, for example, with regard to the philosophical importance of an ethics of care (Tronto, 1993), we could also situate the women's accounts within broader contexts such as socio-historical structures and gain novel theoretical insights. We also remained open to new insights from the data such as women with SCD discussing the importance of various notions of 'careful'. We discussed our data analysis together and decided on the main themes for an accessible report and then more sensitive cuts of data (Layder, 1998), to illustrate theoretical analysis and development.

7. Limitations

There were limitations in our sampling strategy (Bryman, 2015) in that the women who participated were accessing NGO services such as free healthcare, medicine, counselling and education on SCD and to that extent they could be seen as beholden to our key collaborators. The NGOs themselves could have sampled those informants more likely to give positive accounts of the work of the NGOs. To reduce desirability bias (Bryman, 2015) the foreign researcher interjected to probe further if it was sensed that any particular respondent was repeating a socially desirable response merely to please our collaborators. Secondly, due to age, culture and religious backgrounds, the lead interviewers asked that the second interviewer introduce sensitive topics that included quality of marriages, whether or not a woman had had sexual relations, and whether or not they were accessing birth control but this might have also introduced bias. Additionally, the project did not interview any women with SCD in formal employment nor of the highest socio-economic classes. In our sample, women from all ethnicities in were represented (e.g. Temne, Mande, Mandingo, Limba, Maraka) except for the Krio ethnicity who we did not recruit (See Table 1). It is possible that those women are accessing private health care and or services outside of these NGOs.

8. Findings

Using a feminist ethics of care, we explain why mothers, in this study, became morally responsible for care and how moral boundaries are remade through SCD practices. Then we turn to how gendered norms become morally suspended in favour of creation of careful spaces, as attentiveness and responsibilities of care have to become translated into competence (Tronto, 1993, 2013). This changes in early adulthood, as we noted women with SCD being treated differently to

young men. Mothers and women with SCD explained that relationships had embodied risks and in response, we argue women become caring pioneers (Rapp, 1988) to ensure a cautious solidarity.

9. Making mothers morally responsible for caring practices

A moral 'injunction to care' (Gilligan, 1982: 100) lies with women and becomes correlated to their labour as household work. Most women associated the importance of their caring labour within families and having children as part of their duties as a wife, especially within kinship structures where dowries are traditionally paid to a woman's family. Mabinty (36, Freetown) explained this in context of relationship to her mother-in-law:

"I lived with them and laboured for her, cooking, doing laundry, went to the farm and so on. When we were together, I lived with them as one family, as if I am their daughter and that relationship has continued."

The more children a woman had, the more wealth and social status she was accorded, such as in a polygamous household. This 'wealth in people' was emphasised more in older women's stories and in the rural areas where being a 'big man' or a 'big woman' was correlated to accessing labouring bodies (Ferme, 2001). Respondents also reported that the feminine ideal of beauty was correlated to fecundity and visible prosperity. Thus, marriage had several functions in giving standing to a woman but was also connected to expectations of reproduction. Patricia (24, Koidu) clarified this status as 'wife' was also morally enforced by other women in a community:

Patricia: At times when a woman is not married, she is given many names.

Interviewer 2: What are some of the names?

Patricia: She may be called a prostitute, raray girl. When they see her with a man today and a different man tomorrow, they say she is a raray girl, that is why she did not get married.

However, motherhood too accorded women social standing, despite being a third wife in polygamous marriage or even someone's girlfriend. Djenabou (30, Koidu) thus explained, "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."

Participants noted that if a woman cannot have children, children are ill, disabled or die, she will be viewed as morally deficient. Most women thus related having to navigate moral blame which could have a religious, practical, supernatural (e.g. accusations of witchcraft) and even intergenerational dimension (see Marsh et al., 2011). Sally (46, Freetown) noted a historical memory of 'bone pain' in the Mende language but attributed it to the female line:

"They ask who has SS whether it is I or my husband. My grandmother explained that my mother had it. During her last attack (*Kaa gbakpai*) she died. They tie them with clothes (*Ta ngie ngie lo*)."

In aforesaid oral accounts, care practices entailed moral attentiveness, as well as undertaking responsibilities of care (Tronto, 1993, 2013), such as tying *lappa* (cloth) around the part of the body where pain is being felt so it can be eased. The generic principles of Tronto's (1993) 'caring about' were often illustrated by mothers seeking out clinical or traditional medicine for their infants when the first symptoms of SCD appeared. When medical professionals and/or traditional healers could make a diagnosis, this did not provide any relief for the mother. Diagnosis meant the caveat that there was 'no cure' for SCD, meaning blame and/or accusations of witchcraft with life-changing implications, as Bintu (55, Freetown) described when she asked her husband for a divorce, which he refused to give. A grandmother, Khadija (54, Freetown) situated culpability with her daughter's mother-in-law who she said had given them SCD. We heard cases of fathers but

also of mothers leaving their children, meaning grandmothers had to take on care-giving roles. As Kumba (30, Koidu) explained, while crying, “My mum’s family. They do not care about us. They left us; they abandoned us.” How did women mitigate such moral blame and ensure care-giving?

10. Refashioning moral boundaries

While not intentional, at first, blame seemed further enforced by health care professionals and NGO workers in our data, when women were told about the SCD diagnosis. Our key informants Amelia and Sia’s emphasis was on explanations that both parents were responsible for a child with SCD. So, during an interview, Amelia explains, “It’s the two people that join to give birth to a baby. In counselling they tell them that both mother and father have the trait. She has the gene but it does not show.” Similarly, Sia regularly asks if the fathers have been tested, for instance, “Have they checked your husband?” Importing genetic counselling scripts from the Global North, health care professionals also told mothers they were carrying the trait and they ‘should’ get their husbands tested and come together for testing. For example, Ella (29, Freetown) stated: “So, they advised me that my husband and myself go and do the test at (Name of clinic).”

Such caring practices reinforced ideas of women as morally responsible for the health of the family (child and father) but also revealed a clinical anomaly. In Sierra Leone, abortion is illegal and although not always widely available and costly, new-borns can be tested to find out if they have SCD, so why was it deemed necessary to test the fathers? In the Global North, father testing would be in the context of pre-conceptual planning or (where the partners already have a child with SCD) or in voluntary family size limitation (which would run counter to the prevailing culture of valuing many children). We argue that father testing gives the women a moral defence against blame and that this is not unintended but intended consequence of the genetic testing of fathers. This was a conscious motivation on the part of female professionals who advocated such testing, and we explain why.

Mabinty, who had children with SCD, one of whom had died, recounted that not only did her husband refuse to get tested but, “He said he enquired through sorcery and found out that I killed his child. I had quarrelled with someone.” This had grave consequences for her and she explains that a woman is usually an outsider and travels from her village to her husband’s house to become part of his family. If a marriage breaks down, a woman can return to ‘her people’ or village where she is from:

“I became afraid that he might kill me while I was asleep, and so my mum stayed with me for four months. For these children I don’t go to the village. (...) To travel, even the breeze can be a problem such that by the time we reach they may be sick. They don’t have pipe borne water but flowing stream.”

The ‘care-giving’ (Tronto, 1993) that the children with SCD needed, in terms staying hydrated and out of cold and windy weather, meant that she continued to live with her husband. The Harmattan wind and colder air in the provinces during the dry season can lead to a rapid cooling of the skin which is a known trigger for a SCD crisis (Dyson, 2019: 39). This meant an abdication of caring for herself.

However, when fathers did know their status and/or got tested, moral blame was at least potentially distributed more equitably between the father and mother. Zainab (45, Freetown) described how her Nigerian husband told her he had the trait after their child was found to have SCD and was “fully responsible for us”. She did not blame him but states, “So the nurse said, it’s the man that has the sick. He is well established and very responsible person. So, we were going for treatment.” Amelia explained, “The man’s revelation makes the woman to relax. Some men blame the woman in such situations. Acceptance brings relief.” We heard this from the younger women as well, for example, Fanta noted (24, Koidu), “When we came back and everything

was proven, he called me and asked me to forgive him. He also told me that he had known he had sickle cell when he was young.”

For some women, it meant that men also took on care-giving tasks, as Khadija explained, “The man loves the kids and he tries. He knows that the kids are sick through him. When medicine finishes, he tries to get money and purchase them.” The dispersal of fault also gave women more freedoms, for example, it aided a reversal of the moral policing of women by other members of the community. Isha (25, Freetown) described an interaction with her neighbour, “She says that I should divorce my husband and get healthy children.” While women were made responsible for all caring practices (Fisher and Tronto, 1990), moral blame was being heightened before becoming relatively more equally distributed by virtue of mainly female professionals asking men to get tested, remaking moral boundaries so that both genders became responsible for care-giving (Tronto, 1993). In what follows, we turn to how caring ‘competence’ was developed and experienced.

11. Care-giving for boys and girls: suspending gender roles

In many interviews, it was emphasised that men and women undertook care-giving together with support of their families. Women viewed the care they had to give as all-encompassing with the aim of keeping children well and out of hospital. They explained when ‘caring about’ and ‘caring for’ were not reliable, it was ‘care-giving’ and ‘care receiving’ that were most important (Tronto, 1993, 2013). Thus, mothers related they had to go to schools to tell teachers not to ‘flog’ or ‘beat’ their children, explain they had to drink water, go to the toilets regularly and that they were not inattentive in class but experiencing anaemia. Estelle (32, Freetown) described how she paid close attention to if her son was becoming withdrawn or ‘moody’ so she knew when she had to ‘encourage him’. Likewise, other mothers remained watchful for the signs of SCD, like fever, yellow eyes, urine changes, protruding spleens, racing heartbeats or the beginnings of pain as child lost their appetite, became quiet or began to cry.

When we asked about the roles of girls and boys in the household, mothers explained ‘careful’ spaces had to be created. Often inter-generational local and global knowledge of SCD played an important role in contextualising competencies of ‘care-giving’ (Tronto, 1993), like understanding the importance of non-violence and nutrition. Estelle related, “Sometimes I will find a cane when he does something wrong but I was advised by an elderly man not to flog him because of his condition.” Likewise, Harietu (65, Koidu) explained her old age with SCD by her family’s competencies which they had learnt from an expat, for instance, “He told my father that every morning I should have a cup of tea, eat cucumber, pear ... my father did not have that experience.”

In Sierra Leone, there are roles in the home that boys and girls are socialised into. Often girls have to partake in tasks such as cooking, cleaning, laundry and babysitting, and boys may be responsible for laundry, garbage disposal, cleaning or fetching water. However, we noted that for children with SCD many of these heavier tasks were suspended in favour of lighter ones, such as, sweeping. It was related how siblings often felt resentment that children with SCD were given the best food, had more attention and were allocated reduced or even no household tasks. Parents were also very protective of children with SCD, not allowing them to physically exert themselves or play outside when it was very hot or in the rain, as the rainy season was associated with higher rates of SCD illness (see Dyson, 2019: 39). While this might have had a protective individual effect in terms of learning self-care, women with SCD like Amie (23, Koidu) described the costs of such ‘care-receiving’ (Tronto, 1993):

“When they are having fun, you know that if you join them, you will likely go into crisis. (...) They will laugh at you that you do not take part in any of the activities; that you are a HP (*house pikin* or *house child*) or you do not know anything.”

In spite of such consequences, parents were fearful of their children

socialising and kept children within closed communities where people knew about their condition, as its physical effects had other unintended impacts increasing stigma (Ola et al., 2016). Siabanda (19, Koidu) explained:

“My mom took me to Freetown and I was tested again. They confirmed that I had sickle cell, but I wasn't receiving the right treatment. I was getting worse; my stomach was swelling up and my body was also swelling up. When we returned, my family abandoned us. We were asked to move out of our rented house because I would cry throughout the night and they said it was because I was a witch. I stopped going to school because my friends called me a witch. They said the disease could not be treated in hospital; only by native doctors. They even decided to ‘cook’ my stomach; they said that will kill the witch if it was in my stomach.”

In Sierra Leone, and West Africa in general, many oral traditions have a figure of a witch with a distended belly (Shaw, 2002), often where the witches' cauldron or pot is located (Dennis-Antwi et al., 2011) which children with SCD with an enlarged spleen seem to fit. This is a trope that parents tried to address through education to prevent such stigma.

Nevertheless, stigma was often less of a concern than the serious medical consequences of the illness, when it would ‘attack’ and children go into a pain crisis. Parents related helping to manage their children's pain through lay competencies such as massage, keeping their children warm with their bodies and ensuring they had pain relief, which became parts of ‘care-giving’ (Tronto, 1993). As Sally explains, “The father rushes to her and gets hot water for her through the gas stove. Dad hugs her until she sleeps through her dad's warm body. She then sleeps well.” Such deeply embodied ‘care-receiving’ led to children with SCD feeling very attached to their parents. In some families, mothers took morning shifts of care and fathers the evening. Kadie (19, Freetown) elaborated, “Yes I get scared because my father does everything at night but during the day, I expect my mother to be around.” The above illustrates how fixed gender roles in the careful home were suspended both for parents and children. This became important in comprehending how women with SCD were socialised into adulthood.

12. Care-receiving and careful husbands

‘Care-receiving’ and ‘care-giving’ (Tronto, 1993) did not seem to change until children reached puberty. That is when they began to become enculturated by counselling discourses linked to SCD, relationships and parental anxieties. Women with SCD stated they received encouragement to study and to delay marriage. For example, Hawa (38, Freetown), who had both a boy and girl with SCD, said that she did not want either to have relationships but her fears for her daughter, because of pregnancy, were greater. She stated, “I see her making calls, but I advise that since she is sick, let her not develop a relationship with any man.” And later she notes that the daughter is secretive so she does a pregnancy check on her every few months. Isha explained these were real fears in mothers, as she had her first pregnancy when she was only fourteen.

Despite the gendered vigilance linked to sex, there was a lack of knowledge about how SCD affected reproduction. Women who had SCD did not understand if they had long or short periods, if those were heavy or light, when they could get pregnant and that they could go into crisis during their periods (Ross et al., 2015a,b). This seemed very different from information boys had about SCD and their reproductive options. When Jenneh (37, Freetown) was asked about what future she wanted for her sixteen-year-old son, she said to study and work in bank where he would be comfortable. This was exactly the same as we heard in relation to women with SCD and gender norms seemed comparable.

However, when asked if he had a girlfriend, Jenneh noted: “When he finishes his education if he gets a job there is no problem. Even if he gets a girlfriend, then that will be okay.”

Delayed reproduction was fostered by parents as a key part of their strategy for ‘care-giving’ (Tronto, 1993) to ensure children got good jobs and was influenced by the uncertainty about the prognosis of SCD. Yet, we found an enforced ignorance in women was leading to a lack of reproductive justice (Ross, 2015b). Thus Isatta (18, Freetown) asked, “That upon completing my education and I will get married and give birth to children, how would I be like? Will my condition improve with age?” Reproduction, family planning and life-course outcomes were clearly pertinent to decisions around marriage but healthcare professionals, counsellors and even mothers rarely discussed such issues with women, not seeing them as competences of care-giving, but rather framing them as part of religious beliefs or marriage. For instance, Keima (18, Koidu) explained how her pastor stated: “If you are going on with boyfriend business and you die, you will go to hell.”

As explained earlier, this is in keeping with how women's morality was policed but role as mother revered, even if a woman had girlfriend status. However, a double standard came out in all interviews, where while girls with SCD needed extra protection, despite having the same condition it was inevitable that young men with SCD would have girlfriends and children.

Interviewer 1: How old was your son when he impregnated the girl?

Bintu: My son was 21 years.

Bintu displays an attitude that is matter of fact for masculinity and non-judgemental in keeping with societal norms. Compared to discourses around women with SCD, it is almost a little emotionally cold with no sense of the need to protect her son with SCD and even less his girlfriend. In fact, later in the interview we learn that her son has several children with differing girlfriends despite living at home.

In contrast, for women, in addition to delaying marriage, there was an emphasis placed on finding a specific kind of husband. Amie had a boyfriend who knew that she had SCD but she explained that she was deliberate in choosing a man who did not carry the trait. She clarified, “I have to think of tomorrow. I can't think of the love today and then struggle with the children tomorrow.” But she also qualifies, “I will look for man who doesn't have sickle cell and is caring. Someone who will care for me.” Kadie also stated: “I pray to God to have someone to care for me like my dad. He is very caring.” The was dissimilar to experiences of the older women, like Harietu, who recounted how her father said, “If you do not love the man, I will beat you, I will kill you.”

Mothers related that they feared the mental and physical consequences of relationships on girls, which women with SCD corroborated. For instance, Barbara (32, Koidu) explained:

“People look low upon you when you have this illness. Sometimes, I think about it so much and cry that it makes me ill. Men come my way and want to have a relationship. I think that they will stay with me and help me with my children but no; as soon as they are told that I have this disease, they avoid me. I think about it so much.”

Some relationships heightened ill health, for example, partners not being faithful and having girlfriends, the emotional stress of which women claimed caused them to go into crisis. Fanta noted that her relationship difficulties also coincided with children becoming ill and she said: “When my child was ill, that was the time he rented a house for his girlfriend on (name) road.” Women's health was generally made worse by regular experiences of physical and/or sexual violence. This sometimes had an accumulative affect as not all families were caring, teachers could ‘flog’ children, and partners could be very abusive. This meant that even if a woman had a milder version of SCD, she seemed to

have the frequency of crises of someone with the severe version. Gladys (23, Koidu) in her interview explained why this happened:

Gladys: (...) It was surprising each month not to be ill.

Interviewer 1: It was that frequent?

Gladys: Aha. It was by God's grace that is over.

Interviewer 2: I have a question. Were they beating you in school?

Gladys: Yes, they were beating me in school.

Interviewer 2: Did you get a crisis after the beating?

Gladys: Yes, after they beat me in school.

Interviewer 2: How about your husband; is he beating you?

Gladys: My husband?

Interviewer 1: The first one?

Gladys: Ah ... that first one, he was beating me.

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.

Pregnancies also had an accumulative disabling effect, as Harietu notes that she was the younger and most favoured wife of her husband until she started getting ill following pregnancies and they separated. Women with SCD also related fears about their ability to give birth naturally, haemorrhaging and having a still birth – events some had tragically witnessed. Many of the women with SCD also related their experiences of almost losing their lives during pregnancy or in childbirth due to inadequacy of care and need of multiple blood transfusions.

The above explained why careful husbands were being selected and taught (by the mother with SCD) about their duties. Sally, who said she had a good marriage, stated,

"Yes; that is why I had said that you should be with a man who is caring, who is aware that you are a sickle cell patient and will get ill sometimes. In a marriage household, housework will need to be done but you cannot put your hands in water or wash clothes. If the man is aware and is caring, he will arrange for your sister or looked after child (fostered) to be helping you at home."

Yet, in the above, it is still not the man himself undertaking the work of care, he is merely arranging for other women and/or children to do it. Caring is still viewed as a woman's task and associated not with the husband but his female relations. Aminata (33, Freetown) similarly related:

"They accepted because the man was so caring. He was poor but if I was sick and admitted, his mother would stay in the hospital with me until I am discharged because my aunt and the others were occupied with their own business."

In addition, women with SCD were taking control of their 'care-giving' and 'care-receiving' (Tronto, 1993) by gendering SCD and re-fashioning their sexual roles. Gladys, who had a new partner, explained: "I thank God for this man. He is different from the other man I had and is not demanding like that man was. He doesn't insist when I tell him that I am tired."

Despite trying to refashion relationships, in ways such that they could be regarded as being 'careful', women with SCD had little access to reproductive advice (Ross, 2015b). Yenor (23, Koidu) said that her healthcare provider in Freetown had recommended waiting until she was twenty-five to have children but mentioned nothing about contraception. She had to arrange this herself and explains trying several

contraceptive options that caused consequences as severe as heavy bleeding. She recounted, "I am not a virgin but when I meet someone, I tell him outright that I am not yet ready to have a child, so we should use condoms." However, in practice she uses the morning after pill not realising that she is still putting herself at risk for sexually transmitted infections and possibly for complications linked to hormonal contraception interacting with SCD, like venous thromboembolisms.

Although health care professionals and NGO staff, in line with religious and cultural beliefs, did not believe in sex before marriage, it occurred in both urban and rural settings. Participants noted that family planning and access to birth control were ways in which they could care for themselves as mothers and women with SCD, a form of 'caring with' (Tronto, 2013). Women related that they were using birth control to stop having children, like Barbara who needed to look after her health after having three children. Jenneh and her husband agreed that austerity measures meant that they could not afford children and she would implement birth control. Other women did not want more children if their husbands had been violent or had not been tested, so for example, Fanta accessed birth control without her husband knowing. Women noted the importance of cautious private caring practices in a country where there was very limited medical care, regular gender-based violence and limited finances. What does the above tell us about feminist ethics of care in an African setting?

13. Discussion

When examining how an ethics of care unfolds, we noted how mothers and motherhood became a moral site, and initially it seemed as if an 'injunction to care' (Gilligan, 1982:100) only lay with women. Women were responsible for all five aspects of care: caring about (e.g. getting societal and medical resources for SCD); caring for (e.g. raising awareness in communities and schools about SCD); care-giving (e.g. ensuring careful homes and competencies in how to care for a child with SCD); care-receiving (e.g. learning how to care for the self and find a careful husband); and caring-with (e.g. accessing reproductive justice) (Tronto, 1993, 2013). We illustrated how 'caring about' and 'caring for' (Tronto, 2013), while lying in the public realm, were important to morally deflect blame away from women; so that care could also be undertaken by men, healthcare professionals, schools and within communities. Gender roles and caring responsibilities of men are not fixed into patterns, for example of 'blame of mothers' for children with SCD (Marsh et al., 2011) but change over time and are often nuanced by social circumstance. We found that women could also 'blame' fathers (Fulwille, 2011) and men accepted genetic and other responsibilities of care. In this way this study also contributes to studies of masculinity in Sierra Leone, which have often neglected caring intimacies of family life, fatherhood and love.

In this, we argue that women were behaving like caring pioneers (Rapp, 1988) by enrolling global SCD scripts ('test fathers') to refashion caring practices. In the Global North, a certain script, that is a regularised, ready-to-hand way of talking about something, has developed around SCD, namely, 'get tested and know your genotype'. Such scripts have a halo effect of according their users' prestige, and they also function to further identity formation as leaders in the community: they are modern, up-to-date, in the know, educated, scientifically literate and not guided by witchcraft. Women with SCD used such scripts to refashion themselves and to ensure caring practices could unfold with relational and financial resources (Fisher and Tronto, 1990). We found this caring policing by women acted to redistribute blame, rebuild moral boundaries and allowed parents to become attentive and responsible for care-giving together (Tronto, 1993). This also meant that regular gender norms of masculinity were unmade into 'careful' fathering with care practices involving 'themselves, their bodies and total environment' (Fisher and Tronto, 1996: 40).

When examining 'care-giving' (Tronto, 1993), parents were ensuring the creation of careful spaces, compared to the carelessness

(Rogers, 2016), by means of stigmatisation and structural violence, that their children could be exposed to in public. As a result, careful spaces were constructed at home, where gender roles became suspended and these developed into care-receiving practices in adulthood that deflected gendered expectations for women (e.g. stay in education, defer marriage and avoid childbearing) but enforced those for men (e.g. girlfriends are acceptable and have children). Fears of pregnancy, having more children with SCD and violence in relationships, coupled with religious and cultural norms, meant that mothers and women with SCD were inclined to be attentive to discourses of abstinence. Parents were also in favour of their adult daughters studying or waiting for a careful husband who did not carry the trait, in keeping with the genetic counselling scripts they heard from NGOs. Men were also socialised to take education seriously, but no constraints were enforced around their sexuality, despite the fact that, morally, they too shouldered an equal responsibility for having children with SCD.

While both men and women were gendered by their SCD experiences in differing ways, at no point was not having children a socially realistic prospect (see Hill, 1994). It was reproductive timing that mattered morally and this became a part of caring dilemmas and practices where being care-ful, as cautious, became a moral virtue. In the above, we illustrated how careful is used in four senses of the word: Firstly, people with SCD have to be careful or vigilant, so that they don't make themselves ill in fulfilling various societal roles; and secondly, the creation of care-full spaces that are full of care given to and by people living with SCD. What is 'careful' changes as thirdly, careful (cautious) spaces are created where young women with SCD are taught to be prudent to the point of avoiding sexual relationships and pregnancy. Lastly, care-full spaces, full of care and caring emerge, where women share practical wisdoms of how to give care to a child with SCD and how to care for oneself as a woman living with SCD.

The various caring dilemmas centred around becoming careful selves, creating spaces full of care, finding careful husbands and ensuring a careful body - all emphasizing moral caution, illustrating limits to a feminist ethics of care. 'Caring for' and 'caring about' depended upon the additional labour of community patriarchal figures, like Amelia and Sia, and never became part of 'caring with', in terms of care practices as politically valued or (bio)politically a part of reproductive justice (Tronto, 2013). This was further highlighted when we published a public report on our findings with recommendations and a five-point national policy plan (X et al., 2019) which was politically ignored. However, it was taken forward by Amelia and Sia in their practice to improve family planning, ensure psychosocial support and shared amongst their networks. Likewise, ensuring caring husbands had limits as the woman's caring labour would have to be done by his female relatives and/or children. This just displaced the labour of care to women who ended up caring for and together with each other.

In the face of gender based violence, women refashioned care so they could access family planning in conjunction with their husbands or kept it as a secret, as it became part of a private and non-political sociality of a cautious 'caring together' instead of 'caring with' in society (Tronto, 2013). However, this led to ambiguity, as sex, reproduction and violence in relationships were subjects that women could not talk about openly in the public realm. As a result, women with SCD were receiving incorrect and dangerous reproductive advice, as women risked their lives and wellbeing.

Globally, men seem to be the assumed normative model for understanding health in people living with SCD, but there should be more clarity and clinical guidelines about how women with SCD will experience normal bodily functions like periods, which contraceptives are safe, clearer information about pregnancy linked to SCD outcomes and that natural childbirth, with specialised clinical follow-up, is possible. Violence and uncaring relationships were also linked to embodied consequences for women with SCD that all NGO workers and mothers were aware of. Women were developing their own ethical caring practices and scripts in an African setting correlated to management of

embodied and other forms of violence, for example, finding a man who did not have the SCD trait and would be a 'careful' husband. This points to a lack of guidance around SCD and gender-based violence, as well as impact of careful spaces and relationships which health care professionals should learn from. Lastly, global public health scripts that declare children with SCD 'burdens' and a lack of investment in medical care, are also forms of violence and coercive control over bodies and lives of women as they have to live the policy impacts of a global neglect of SCD. We thus also noted that there was a silencing of grief over loss of children with SCD that lay at the heart of caring practices, that key informants like Amelia and Sia were challenging, by seeking to render the invisible private, a matter of public policy.

14. Conclusion

While men are viewed as the embodied standard in SCD, it is the female SCD body that shoulders the physical and moral workload and it is women and mothers (like our key informants Amelia and Sia), who have to deal with the embodied consequences and rebuild boundaries of care. While a feminist ethics of care can illuminate such practices, as we have illustrated, it is obliged to do so cautiously in the face of gendered structural and intimate physical violence, and to this extent the practical efficacy of feminist ethics is reduced. Instead African women become caring pioneers and refashion care to ensure that they can privately 'care together with' women with SCD, thereby giving them small moral freedoms by creating careful relational spaces in a patriarchal society where structural violence remains the norm.

Credit author statement

Berghs, M. (design, interviewing, translation, Formal analysis, theoretical framework, writing up); Dyson, S.M. (design, Formal analysis, theoretical framework, writing-up); Gabba, A. (design, interviewing, translation, data-analysis, writing-up), Nyandemo, S.E. (interviewing, data-analysis, writing-up), Tregson, G. (design, data-analysis, writing-up), Deen, G. (design, data-analysis).

Table 1

No.	Pseudonym	Location	Person with SCD and/or Mother	Age	Ethnicity	Literate	Religion
1	Estelle	Freetown	Mother	32	Loko	Yes	Christian
2	Susan	Freetown	Mother and person with SCD	30	Sherbro	Yes	Christian
3	Aminata	Freetown	Mother and person with SCD	33	Temne	Yes	Muslim
4	Fatmata	Freetown	Person with SCD	23	Temne	Yes	Muslim
5	Sarah	Freetown	Mother	42	Limba	No	Christian
6	Mariama	Freetown	Mother	39	Sherbro	No	Christian
7	Hawa	Freetown	Mother	38	Susu	No	Muslim
8	Jenneh	Freetown	Mother	37	Susu	Yes	Muslim
9	Isatta	Freetown	Person with SCD	18	Temne	Yes	Muslim
10	Mabinty	Freetown	Mother	36	Mende	No	Muslim
11	Zainab	Freetown	Mother	45	Mende	No	Muslim
12	Sally	Freetown	Mother	46	Mende	No	Christian
13	Kadie	Freetown	Person with SCD	19	Limba	Yes	Christian
14	Khadija	Freetown	Grandmother	54	Temne	Yes	Muslim
15	Isha	Freetown	Mother	25	Temne	No	Muslim
16	Fatima	Freetown	Person with SCD	23	Temne	Yes	Muslim
17	Bintu	Freetown	Mother	55	Temne	No	Muslim
18	Ella	Freetown	Mother	29	Temne	Yes	Muslim

(continued on next page)

Table 1 (continued)

No.	Pseudonym	Location	Person with SCD and/or Mother	Age	Ethnicity	Literate	Religion
19	Siabanda	Koidu	Person with SCD	19	Kono	Yes	Christian
20	Finda	Koidu	Mother and person with SCD	45	Kono	No	Christian
21	Kumba	Koidu	Mother	30	Kono	Yes	Muslim
22	Suma	Koidu	Mother	30	Kono	No	Christian
23	Djenabou	Koidu	Mother	27	Fula	Yes	Muslim
24	Yara	Koidu	Mother	35	Kono	Yes	Muslim
25	Fatu	Koidu	Person with SCD	27	Limba	No	Christian
26	Yenor	Koidu	Person with SCD	23	Kono	Yes	Christian
27	Barbara	Koidu	Mother and person with SCD	32	Kono	No	Muslim
28	Isata	Koidu	Grandmother	67	Limba	No	Muslim
29	Sera	Koidu	Person with SCD	22	Limba	Yes	Christian
30	Amie	Koidu	Person with SCD	23	Mende	Yes	Christian
31	Dawa	Koidu	Person with SCD	30	Kono	No	Muslim
32	Patricia	Koidu	Person with SCD	24	Kono	Yes	Christian
33	Gladys	Koidu	Mother and person with SCD	23	Kono	Yes	Christian
34	Fanta	Koidu	Mother	25	Maraka	No	Muslim
35	Keima	Koidu	Person with SCD	18	Kono	Yes	Christian
36	Harietu	Koidu	Mother and person with SCD	65	Madingo	No	Muslim

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Appendix A. Supplementary data

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