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RESEARCH ARTICLE



# How a child's gender mediates maternal care and expectations in the fatigue experiences of adolescents with sickle cell disease

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## ABSTRACT

Despite the chronicity and biopsychosocial significance of fatigue in sickle cell disease (SCD), it is rarely prioritized in understanding illness experiences and the social consequences of SCD for children, young people and their families. This study examined fatigue's social meaning and significance for young people with SCD. This examination involved perspectives on parental (maternal) care/support. We adopted a constructivist grounded theory approach. Data for the study was gathered from 24 purposively sampled adolescents with SCD in Ghana. A multi-method approach, combining semi-structured and photo-elicitation interviews, was used to generate data to ensure comprehensiveness and credibility. The findings indicated that adolescents with SCD perceived their gender to mediate their mothers' care and expectations. According to them, their mothers' interpretations of the significance of SCD for them were dependent on gendered cultural norms. The girls described their mothers as prioritizing their ability to conform to gendered expectations over their illness and limitations. By contrast, the boys presented their mothers as prioritizing their illness over meeting gendered expectations. In conclusion, gendered parenting practices influence adolescents' social status, sense of self, and ability to pursue independence and self-care. Consequently, cultural (gender) expectations should be considered in parental education and family interventions targeting chronically-ill children.

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## KEYWORDS

Sickle cell disease; chronic illness; fatigue; gender; Ghana; parenting; young people

## Introduction

Norms of caring for a child with a chronic illness alongside being a parent and agent of socialization can be challenging for parents and their children to negotiate irrespective of context. Contemporary notions of children's bodies being at risk and needing protection and the notion of children's bodies being 'unfinished' and in need of work and guidance

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imply that children are regularly monitored, assessed and controlled (Kelle, 2010; Lupton, 2013). When a child has a chronic illness, the issue of control becomes even more salient. Parents are expected to monitor their child's illness closely and take action if their child is 'non-compliant' (Kelle, 2010; Lupton, 2013) whilst ensuring children are socialized to conform to societal expectations (Maccoby, 2000). Embedded in this idea is a narrative of responsibility; if parents are unable to manage their child's illness and at the same time socialize them in an 'acceptable' way, they risk being perceived as deficient at a personal level (Pals et al., 2020). How parents negotiate their responsibilities can have social consequences for a child with chronic illness, particularly in adolescence, as they seek autonomy, independence, and pursue self-care (Pals et al., 2020). Consequently, it is important to explore young people with chronic illnesses' perspectives on parenting and their views on the implications for their health and development.

Gender and its associated cultural expectations are understood to be an important construct shaping parenting and children's socialization (John et al., 2017; Mayall, 1996). However, specific evidence on how parental care may be influenced by gender in the case of a child with a chronic illness is limited. The available evidence suggests that a child's gender does influence maternal involvement in those contexts which have been researched, including a UK-based study about diabetes self-management practices (Williams, 1999, 2000) and a US-based study about parenting styles adopted for children with sickle cell disease (SCD) (Hill & Zimmerman, 1995). Williams (1999, 2000) reported that mothers of teenage boys with type 1 diabetes were more involved in their self-management practices than the teenage girls' mothers. The teenage girls in the study felt they were expected to be more self-caring.

This present study adds to the literature by examining the fatigue accounts of 24 adolescents with SCD in Ghana and their perceptions of parental (maternal) care/support and expectations in relation to their symptom/illness. Our analysis is centred on how adolescents report experiencing maternal care, constraints and expectations and how they perceive their gender to mediate this. In the following sections, we discuss the context of childhood, parenting and socialization in Ghana and review the socio-cultural context of caring for a child with SCD.

### ***Childhood, parenting and socialization in Ghana***

Research on the social construction of childhood in Ghana is virtually non-existent. Scholars have been left to rely on childrearing practices in different ethnic groups in Ghana (in some cases, their own childhood experiences) to make intellectual inferences on the concept of childhood (Boakye-Boaten, 2010). Symbolically, a child constitutes the pivotal point in life within the Ghanaian traditional value system due to their perceived fundamental role as future insurance for families and perpetuating family and cultural mores (Boakye-Boaten, 2010). A child is also perceived as passive and has to learn to adapt to the requirements of society. In general terms, children are socialized to obey and conform to cultural expectations and standards, with any deviation disapproved of and discouraged (Salm & Falola, 2002).

In Ghana, personhood is seen as only acquired during functional maturation. Consequently, parenting is pragmatic, apprenticeship-like, and aims to systematically

‘graduate’ children from one social role to another until they assume adult roles. Thus, a child’s social and cultural development is mainly based on the values attributed to physical work. Given this, it is common for children to participate in housework and other minor economic activities (Adu-Gyamfi, 2014; Boakye-Boaten, 2010). Nonetheless, children are considered immature and incapable of making decisions until the agreed threshold of adulthood is reached, which culturally is defined by marriage or the acquisition of a trade (Adu-Gyamfi, 2014; Boakye-Boaten, 2010). Although Ghana is a multi-ethnic society, values and childrearing practices seldom show variations among the different ethnic groups (Adu-Gyamfi, 2014).

Gender is a fundamental construct shaping parenting and socialization in Ghana, influenced by the cultural hierarchical power structure, which positions children, and girls in particular, at the bottom (Adu-Gyamfi, 2014). Most children acquire a social understanding of gendered norms within the home setting from a young age (Chant & Jones, 2005; Salm & Falola, 2002). Gender representations in Ghanaian culture are predominantly binary. Girls are traditionally socialized by their mothers from an early age to focus on domestic industriousness as preparation for marriage and motherhood (Salm & Falola, 2002). Their household chores contribute to the family’s cultural, social and economic functioning and accentuate under conditions of family financial stress and challenges (Bray, 2003).

In contrast, boys’ socialization traditionally emphasizes physical activities that require strength, competitiveness, and aggression, with educational and occupational success as long-term goals (Salm & Falola, 2002). Therefore, they are permitted more time to play and be away from the home to develop and demonstrate culturally expected masculine characteristics (Chant & Jones, 2005; Nukunya, 2003; Salm & Falola, 2002). Fathers have the primary cultural responsibility of socializing their sons into gender and cultural norms. Indeed, ‘successful’ parenting is culturally judged on a child’s ability to conform to these gendered norms during adolescence and adulthood (Nukunya, 2003; Salm & Falola, 2002).

Of course, parenting is not static in any culture, and the traditional concept of childhood, along with childrearing practices, parenting and socialization in Ghana, are evolving. This change is attributable to economic, socio-cultural and political dynamics influenced by the cultural invasion from dominant Western cultures that happened with colonialism, and now more rapidly with globalization (Boakye-Boaten, 2010). Nonetheless, the influence of gender norms and expectations on childhood, parenting and socialization persist even in contemporary Ghana.

### ***Caring for a child with SCD***

SCD is the most common severe inherited chronic blood disorder in children and adolescents globally, occurring predominantly in sub-Saharan Africa (Piel et al., 2013). It is a complex and variable chronic condition characterized by life-threatening and life-limiting recurrent acute pain episodes and chronic fatigue, and the risk of disabling complications such as stroke and multi-organ damage (Mulumba & Wilson, 2015). Pain and extreme fatigue are often triggered by dehydration, extremes of temperature, and emotional and physical stress (Poku et al., 2018; 2020). In children and adolescents, SCD negatively affects overall quality of life and is associated with lower physical

functioning, peer and family relationships, academic performance and psychological adjustment (Poku et al., 2018).

Daily management of SCD involves multiple components, including closely following treatment recommendations, ensuring health maintenance practices (keeping hydrated, keeping warm, resting, avoiding arduous physical activity and being attentive and responsive to signs of possible pain episodes), monitoring health status, and managing how the illness impacts psychosocial and physical functioning (Dyson et al., 2011). Therefore, SCD management constitutes a significant focus and severe disruption in the lives of children and their parents.

The broad role of gender in caring for a child with SCD has been explored in the US, UK, Canada and Sierra Leone (Atkin & Ahmad, 2000; Berghs et al., 2020; Burnes et al., 2008; Hill & Zimmerman, 1995). One aspect is the gendered nature of caregiving roles between mothers and fathers. Research exploring the daily lives of families with a child with SCD has revealed that mothers are more involved in the regular care of their children than fathers, assuming the dual role of being a mother and a primary caregiver (Atkin & Ahmad, 2000; Berghs et al., 2020; Burnes et al., 2008). Aside from caregiving, mothers of children with SCD are also reported to primarily manage their child's socialization and the family's emotional stress related to the child's condition (Burnes et al., 2008; Hill & Zimmerman, 1995). Research suggests that fathers may leave the caregiving and socialization of a child with SCD to mothers as a way of coping with their child's illness and limitations (Atkin & Ahmad, 2000; Burnes et al., 2008; Berghs et al., 2020).

### *The effect of gender on parental caregiving*

However, another important component to understanding the intersection between gender and chronic illness is how a child's gender might affect parental caregiving. As we have noted above, a study involving African-American mothers of children with SCD in the US found that the gender of a child with SCD significantly influences mothers' caring practices, with mothers of boys seeing their sons as more vulnerable than mothers of girls (Hill & Zimmerman, 1995). Mothers of boys were reported to be more likely to restrict their children's activities than mothers of girls. Such overprotective behaviours of mothers of boys were found to be associated with poor adjustment in their sons. Hill and Zimmerman also consider the role of specific cultural expectations in influencing parental care in SCD. They observe that mothers of sons were more likely to perceive their children as sicker, although the authors could find no evidence that they were. Consequently, mothers of sons invested more effort in their caregiving than did mothers of daughters, who described their children as more willing to exercise sound judgment and self-care. The authors conclude that the gendered structure of expectations and opportunities available to Black people significantly influenced caregiving.

These reported gendered differences in caring for a child with chronic illness are likely to be culturally influenced. This article aims to contribute further to our understanding of the intersection between gender and chronic illness by drawing attention to cultural (gender) dimensions of parental (maternal) care and support of children and young people with chronic illnesses in an African context. We focus on Ghanaian adolescents with SCD perceptions of how their gender mediates maternal care, support and expectations, and its implications for their health and development.

## Research method

The findings reported in this paper are from a study that explored SCD-related fatigue in adolescence from the perspectives of adolescents with SCD in Ghana. The study was rooted in constructivist grounded theory methodology (Charmaz, 2014). This methodology acknowledges that knowledge is socially situated and constructed through social interactions with others. It also emphasizes that data generation and analysis are co-constructed by the researchers and participants who bring their ideas, experiences, views and interactions to shape the research process and outcomes (Charmaz, 2014).

### *Recruitment and sampling*

Participants were recruited from two SCD treatment centres in Ghana, located in Ghana's two major cosmopolitan cities, which serve as the main SCD referral centres. Participants were eligible for participation if they were aged 12–17 years and could communicate effectively in the English and Twi languages (commonly spoken languages in Ghana). To ensure that data generated related to SCD (because fatigue is associated with many illnesses and pregnancy), participants were eligible for participation if they had no other comorbidities or were not pregnant. Clinicians at the clinics introduced the study to eligible adolescents and their parents. The first author was introduced to those who expressed interest in the research and provided detailed information about it and what their involvement would entail. Adolescents and their parents who continued to express interest gave their mobile phone numbers to the first author for her to contact them two days later. This researcher-initiated contact was used to address any potential financial barriers to contact. The adolescents and their parents were contacted by phone by the first author two days later to answer any further questions and determine their decision. Verbal assent and consent were taken from both the adolescent and a parent, and the place and time for an interview were negotiated. Written assents and consents were taken at the time of an interview.

Initially, participants were purposively sampled to ensure maximum variation in relation to sex, age, place of residence, educational level, and family socioeconomic background. We relied on the clinicians to help identify participants with varying demographic characteristics to achieve the maximum variation. As the study progressed, theoretical sampling was incorporated to seek out data for conceptual development (Charmaz, 2014). Twenty-four adolescents with diverse demographic characteristics and family circumstances participated in the study (Table 1).

### *Data collection*

We employed multi-method and art-based approaches to engage and support the adolescents' views and the expression of their perspectives as capable social actors (Poku et al., 2019). We used traditional semi-structured interviews, drawings, photography and picture-elicitation interviews (PEIs) to co-construct data with the adolescents. Because our study was interested in adolescents' interpretations of their lives, they were encouraged to produce their own images that reflected their experiences for

**Table 1.** Participant demographic characteristics.

Characteristics	n (% <sup>a</sup> )
<i>Number of participants</i>	
<i>Sex</i>	24 (100)
Male	12 (50)
Female	12 (50)
<i>Age</i>	
12–14 years	13 (54)
15–17 years	11 (46)
Mean age	14.5 years
<i>Educational level</i>	
Primary School	5 (21)
Junior High School	8 (33)
Senior High School	9 (38)
Out of school	2 (8)
<i>Residence</i>	
Metropolitan areas	11 (46)
Suburban areas	13 (54)
<i>Parental Occupation</i>	
Professionals	16 (33)
Trading	24 (50)
Commercial Driving	3 (6)
Farming	3 (6)
Fishing	1 (2)
<i>Single parent household (single mothers)</i>	6 (25)

<sup>a</sup>rounded to the nearest whole number.

discussion. This approach, referred to as auto-driven PEIs, is widely used in research with children and adolescents (Ford et al., 2017). The participating adolescents were given one week to capture their images and complete control over the pictures they produced and shared. They had the option to participate in an auto-driven PEI or a traditional semi-structured interview based on their interest, preference and convenience. In the auto-driven PEIs, the participant-produced images elicited more extended conversations and generated richer narratives than the traditional semi-structured interviews. The discussion of the images created deeper insights and helped to inform the analysis of the data generated from the traditional interviews (Poku et al., 2019). Fifteen adolescents participated in the traditional interviews, and nine participated in the auto-driven PEIs.

Interviews occurred in participants' homes, schools, parents' workplaces, or clinics, depending on the adolescents' and their parents' wishes. Interviews were held privately with the participating adolescents, except for two where mothers insisted on observing the interactions.<sup>1</sup> An interview guide, as well as participant-produced images, guided the interviews. The initial interview guide (see Box 1) consisted of topic areas such as definition/description of fatigue, consequences of fatigue, and self-care and support. As the study progressed, the guide was revised, evolving into an aide-memoire of four main topic areas: representation of fatigue; socio-cultural issues influencing fatigue experiences and support; the interaction between fatigue, identity and social relationships; and interactions between fatigue, identity, self-care and support. This is in line with the constructivist grounded theory approach. Interviews were conducted in English and/or Twi. With permission, they were audio-recorded, fully transcribed, and translated into English (by the first author), where necessary.



**Box 1. Initial interview topic areas.****Main Topic Areas**

1. Experience of living with sickle cell disease in general
  - Daily life with sickle cell and severity of the condition (symptoms, hospital stays)
  - Impact on everyday life (physical, social, educational/academic, emotional/mental)
  - Influence on relationships – parents, siblings, peers, teachers
  - Self-management – practices, challenges/difficulties, challenges in different contexts (home, school, neighbourhood/community), support (sources, types, helpful/unhelpful), support needs
2. Experience of fatigue
  - Nature of fatigue – description of fatigue, explanation of the feeling of fatigue
  - Impact of fatigue – physical, social, educational/academic, emotional/mental
  - Factors influencing fatigue- contributory factors, alleviating factors, contextual (personal, family, social, educational)
  - Concerns and worries about fatigue
3. Self-management of fatigue
  - Day-to-day self-care – practices, experiences, challenges and concerns
  - Challenges in different environments – home, hospital, school, neighbourhood/community
  - Views about current support (forms, sources, helpful and unhelpful support)
  - Support needs and perceptions of unmet support needs

**Data analysis**

The data, consisting primarily of interview transcripts, were pseudonymised.<sup>2</sup> Transcripts were analysed according to the principles outlined by Charmaz (2014), beginning with line-by-line coding of the first four interview transcripts. The codes generated were sorted into analytical (focused) codes. During coding, gaps identified in the data guided subsequent interviews (Charmaz, 2014). The focused codes were used to analyse subsequent data. As coding continued, the focused codes were refined, and new ones were generated as new threads for analysis became apparent. The focused codes were subsequently compared and grouped into overarching categories and subcategories. The properties of the categories were identified, defined, related to each and refined further through data collection and coding to theorize the participants' fatigue experiences. Informal memos were written, and diagrams were drawn to develop ideas about the data and visualize connections between the categories. Participant-produced images were not analysed but used for illustrative purposes only.

By exploring the socio-cultural factors that influenced the adolescents' fatigue experiences during data generation and analysis, we were able to tease out the interactions between gender and fatigue and situate the adolescents' experiences within broader gendered norms embedded within the Ghanaian society. This was central to understanding how gendered socialization norms and expectations influenced parental care and expectations in the accounts. Although parents' views were not explored directly, the interpretations generated from the adolescents' narratives raised important issues about how the sex of a child with SCD and the associated gendered expectations may influence parental care. Indeed, mothers' expectations was a strong thread throughout the participants' narratives, and mothers were the primary caregivers in the data.

### **Rigour**

The principles of grounded theory by Charmaz (2014) highlighted above were applied to ensure rigour in the conduct of the study and interpretation of the outcomes. We employed (a) multi-method data collection approaches and recruited from two settings to ensure comprehensiveness and credibility of the data generated; (b) purposive and theoretical sampling to ensure variation in the sample and data; (c) line-by-line coding, constant comparison, searching for deviant cases, and memo-writing to maintain the trustworthiness and authenticity of the data generated; and (d) theoretical sensitivity to stimulate reflection on the data. We acknowledge that data and analysis are co-constructed by the researchers and participants, who bring their ideas, experiences, views and interactions to shape the research process and outcomes. Given this, we took a reflective stance by thinking critically about our experiences and assumptions (clinical and non-clinical) might have influenced data generation and analysis. We discussed the developing codes, categories, relationships and interpretations being made to ensure the authenticity of the findings generated.

### **Ethics**

Four ethical review committees of two universities and two teaching hospitals granted ethical approvals for the study. In Ghana, parents have the absolute power to make decisions on behalf of their children up to 18 years. Informed consent was considered a family decision, to conform to this socio-legal requirement while acknowledging the international legislation on children's rights. Only participants who willingly assented and whose parents provided consent were interviewed. The adolescents' consent to the study was viewed as a process rather than a single event (Warin, 2011). Attention was paid to their verbal and non-verbal cues and behaviours to remain sensitive about their voluntary participation throughout the interviews. They were guaranteed their right to withdraw from the research at any time, and they were shown how to express such rights using flashcards. Arrangements were made with designated clinicians at the clinics to provide post-interview emotional support where necessary and to handle any disclosure of harm or abuse.

All the generated data (interview recordings, transcripts and participant-produced images) were pseudonymised. Being aware that once images are in the public domain, they are permanent and thus, even if young people and their parents readily consent to the use of the images without anonymising, their perspectives may change in the future (Ford et al., 2017). Therefore, all identifiable features in the young people's photographs were anonymised.<sup>3</sup> The participating young people were encouraged to either limit the photography to themselves and relevant objects or obtain permission from non-participants (family and friends) appearing in their photographs to ensure the safety of non-participants captured in their images.

### **Findings and discussion**

Analysis revealed that participants gave repeated accounts of gendered differences in parental care and expectations. We begin our discussion with examples of parental expectations and the receipt of care/support as perceived by the girls, followed by the boys. We then discuss the implications of the different care and expectations for the

adolescents’ illness experiences. It is important to note that this analysis emanates from a study about the fatigue experiences of adolescents with SCD in Ghana. It is, therefore, unsurprising that physical and social activities featured significantly in the adolescents’ accounts of parental care and expectations. Physical stress is a significant trigger of SCD-related pain and fatigue, such that resting and avoiding arduous physical and social activities are recommended SCD health maintenance practices (Dyson et al., 2011). There was an immediate clear gender difference in the kinds of physical and social activities the adolescents described in their narratives regarding parental expectations and care/support, which reflected cultural expectations. While the girls’ physical and social activities focused on housework, the boys’ were centred on leisure activities outside of the home (social and sports activities). See Table 2 below for a summary of the generated categories and subcategories. The discussion of the categories/subcategories are supported in the following sections of the paper with verbatim quotes and, where applicable participant-produced images.

**Parental (maternal) care and expectations of girls – housework**

Without exception, the girls spoke of having no maternal expectations regarding housework in early childhood. For example, Miss Malaika (aged 15, metropolitan area) said:

Previously, I wasn’t doing anything at all; my mother and my big sister did everything in the house: cooking, cleaning, fetching water, doing the shopping. My mum was even bathing me until I was 10. So, I did not get tired. Mum started introducing me to domestic chores when I was 10. That was when I started feeling tired quickly and frequently. She thought I was old now to learn and contribute to house chores. I understand what she’s trying to do [train me as a female], and I know I must do them and like doing my chores, but they get me so tired.

In this excerpt, Miss Malaika conveyed being less active in early childhood due to exclusion from housework by her mother. She portrayed this exclusion as a form of support, which impacted positively on her illness experience. However, in her narrative, adolescence came with different maternal expectations and attitudes regarding housework. She explained how her mother instituted gendered expectations by withdrawing the previous housework restrictions and assigning her specific chores. Miss Malaika understood the change as a ‘normal’ gendered expectation. She described a sense of responsibility and obligation towards her chores; however, she was conscious of how they negatively influenced her fatigue. Other girls in the study shared Miss Malaika’s perception of her mother’s expectations of domestic duties. Housework was reported as a common factor in their fatigue narratives and featured in some of the pictures they produced

**Table 2.** Summary of relevant categories and subcategories.

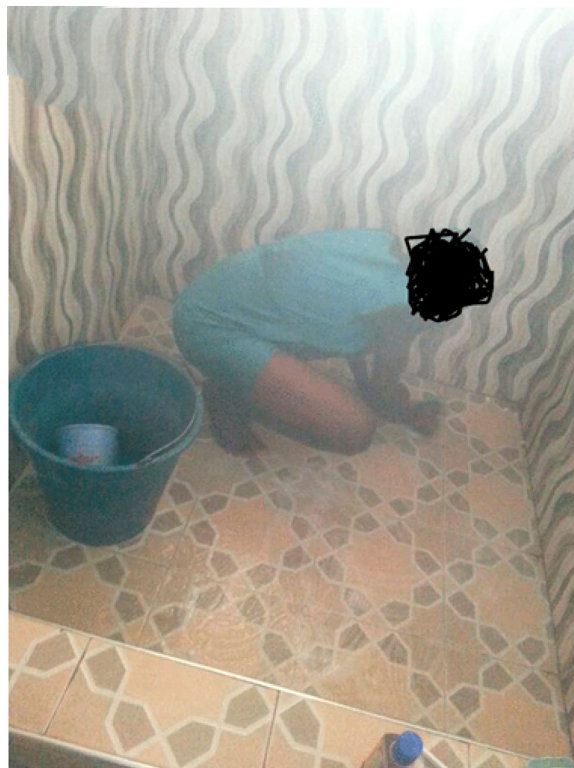
Categories and subcategories
<ul style="list-style-type: none"><li>• Parental (maternal) care and expectations of girls</li><li>• Parental (maternal) care and expectations of boys</li><li>• Implications of parental care, constraints and expectations<ul style="list-style-type: none"><li>○ Social status</li><li>○ Sense of self</li><li>○ Independence and self-care</li></ul></li></ul>

and shared with us. Shy Girl's (aged 17, metropolitan area) narrative and pictures were typical:

I wash utensils, fetch water, and do the laundry. I go to the market for groceries, pick up my nieces from school and prepare dinner. I also scrub the bathroom ([Figure 1](#)), mop the floor ([Figure 2](#)), sweep ([Figure 3](#)) and pound 'fufu' ([Figure 4](#)). There's no energy, time or space left for playing and spending time with friends and even for school work.

Shy Girl's last sentence in the above extract also reveals a common experience reported by the girls: the burden of housework made it challenging for them to manage their other activities – peer interactions and school work. Time and energy management strategies, such as energy conservation and diversion, are important resources in the self-care toolkit of adolescents with SCD (Poku et al., 2020). These strategies enable adolescents with SCD to manage their bodies and fatigue to meet the expectations and responsibilities of growing up (Poku et al., 2020). This conflict between the ability to self-manage and the need to perform expected chores led girls in the sample to portray their mothers as unsupportive of their self-care practices. As Harver Glorious (aged 16, sub-urban area) noted:

My mum says my role is getting the house chores done. I know I must do house chores, they're my responsibilities, and I do them but not at the speed she wants because when I'm doing them, I have to be taking rest breaks and have to be doing them slowly. If not, I'll get tired fast. When she sees that, she thinks and complains I'm being lazy or don't want to do my



**Figure 1.** Shy Girl scrubbing the bathroom.



**Figure 2.** Shy Girl mopping the floor.

chores. When I complain I'm tired and need to rest, she says, 'no man likes a lazy woman'. When I try to make my point, she gets angry and says I'm a disrespectful, spoiled child.

In this moving account, Harver Glorious conveys how her attempt to draw her mother's attention to the impact of housework on her health was motivated not to seek an exemption from it but instead by consideration for her physical capacity and tiredness. By her account, instead of being offered understanding and consideration, this was met with disabling responses – being labelled as 'lazy', 'spoiled' and 'disrespectful'. This leads her to present her mother as insensitive and unsupportive towards her illness and self-care. Harver Glorious also describes her mother as prioritizing her gender socialization work over illness management. This sense was echoed by Barbie (aged 13, metropolitan area), who described how her mother was preoccupied with socializing her to become domesticated for her future gender role:

She [mother] does not understand my tiredness. I see that she's trying to train me to be like her, a good woman in the future, knowing how to take care of a home and children, but that's all she's concerned about, not about how these chores affect my health or how the things she says to me affect me.

Barbie describes her mother as concerned only with socialization into a gender role seen as 'good' or culturally appropriate for an adult female rather than her illness. Both Harver Glorious and Barbie's accounts present their mothers as insensitive to their illness and unsupportive of their self-care. Although Barbie's accounts mitigate her mother's





**Figure 3.** Shy Girl sweeping the corridor.

actions by invoking her inability to understand her fatigue's disabling effects, in both accounts, mothers are described as dismissive of the adolescents' attempts to communicate their experience.

Even where families had additional support for housework in the form of a maid and/or household gadgets, mothers were still presented as viewing the adolescents' socialization into their gendered role as paramount, as asserted by Ramisbeadz (aged 15, metropolitan area):

I don't do much at home because we have a maid. I only help with the cooking, and at times, I bathe my siblings. My mum said I couldn't be a girl and not do anything in the house; that's why I help with the cooking and caring for my siblings. I don't do the washing in the house, there's a washing machine, but I help to air them.

In the account, the availability of additional support for housework still does not exempt Ramisbeadz from housework. While she reports having fewer chores, she is expected to meet gendered expectations. As in the previous narratives, Ramisbeadz's narrative presents no indication that she can negotiate her domestic responsibilities with her mother or have agency in housework scheduling. Mothers were presented across the narrative as inflexible and controlling. This perceived lack of autonomy led some participants to talk about how this could change in the future. Maabena (aged 17, suburban area) talked about looking forward to independent living in order to be able to control her activities and implement her self-care practices:



**Figure 4.** Shy Girl pounding 'fufu'.

When I become independent or leave home for university, I'll ensure that I clean after myself always so that I don't work so much. I'll also schedule house chores based on my energy levels, do some in the morning, and others in the evening, some on weekdays and others over the weekend. This will help me to be able to meet the energy demands.

In this extract, Maabena indicates the strength of gender socialization. Despite her limited energy levels, she does not reject the need to do her chores but simply seeks autonomy in scheduling them. Taken together, the analysis presented above highlights how the girls in the sample perceived their mothers' prioritization of gendered socialization work over the adolescents' illness, ability, self-care, peer interactions and school work. Cultural expectations of mothers are likely to influence this. In Ghana, a girl's ability to meet gendered expectations and succeed in their traditional roles culturally reflects positively on their mothers' parental skills and contributes to the family's image within the community (Salm & Falola, 2002). Mothers are accorded respect when their daughters conform to cultural expectations (Nukunya, 2003). Thus, mothers are themselves subjected to cultural expectations, and they are at risk of being perceived as irresponsible if they fail to socialize their daughters for their future gendered roles. Pressured to raise their female children with SCD to conform to these cultural expectations may lead to them appearing unconcerned about their daughters' health

and unsupportive of their self-care practices, socialization with peers and school work. In addition, there is the possibility that mothers might feel the need to ‘compensate’ for a daughter having SCD. There may be a perception that teaching a daughter with SCD to be a homemaker might help counteract the stigma related to SCD in terms of marriage (Berghs et al., 2020; Dennis-Antwi et al., 2011).

### ***Parental care and expectations of boys – leisure activities***

Boys also presented their mothers as controlling their activities in early childhood; like the girls, they reported that these restrictions had a positive influence on their fatigue, as Atom (aged 16, metropolitan area) noted:

When I was younger, I did nothing. My mother wouldn’t let me do anything. I only played with toys or video games with my siblings, so I hardly got tired. But when I got to junior high school, I started spending time with my friends and playing football. That brought a lot of tiredness and pain crisis.

According to Atom, his mother encouraged being indoors in early childhood and limiting social interactions to non-physical activities with siblings. In adolescence, Atom started to become more physically and socially involved with peers and in sports, as expected developmentally and culturally (Michaud et al., 2007). His last statement in the extract above reveals a common experience among the male participants: that social and physical activities were associated with increased SCD-related symptoms. According to them, this then led to maternal restrictions on social and physical activities persisting throughout adolescence. Hazzard (aged 14, suburban area) describes this below:

The last time I participated in an inter-school football tournament, I came home very tired. My mum later told the headmaster to exempt me from football and all sport games. I don’t like what she’s doing, but I understand her; she is trying to protect me because of sickle cell. But I sometimes play with my friends, and some adults will come and report to her, and she will tell my dad to be strict on me.

Interviewer: who are the adults?

Hazzard: Some of the neighbours that my mum has told about my illness and asked them to keep an eye on me.

Here, Hazzard conveyed how his mother’s restrictions extended to the school context, with her demanding that school authorities exclude him from physical activities. Outside of school, he speaks of his mother involving the authority of other significant adults to help reinforce her restrictions. According to the participants’ accounts, maternal restrictions appear to apply to all social and physical activities, as demonstrated by Captain America (aged 13, suburban area) in the extract below:

She expects me to stay at home always and not participate in any physical activities. Not to even spend time with my friends. I understand her; she is trying to protect me from getting tired and sick.

In this extract, Captain America talks about his mother expecting non-participation in any form of physical activity. The restriction also involves staying at home and avoiding any interactions with peers. This was emphasized by the pictures he produced:



Football (Figure 5) is the main activity that I love, and I'm passionate about, but because of my illness, my mum said I shouldn't be playing it, so now I spend most of my time at home playing video games on my computer (Figure 6)

The restriction from his mother is despite him reportedly knowing which activities make him tired and how to manage this:

I feel tired when I play football with my friends. I can only play for 10 min, so after 10 min, I leave and play video games. I know what makes my tiredness worse, and I avoid them. Also, I try not to push myself.

Captain America vividly demonstrates experiential knowledge of how football affects him, along with the other triggers of his fatigue. This has led to his self-care practices – avoiding pushing his body and alternating his physical activities with non-physical ones when tired. His account describes a consciousness of his capacity limits and a knowledge of the activities that are arduous for him. However, his account suggests that his mother's expectations and restrictions operated independently from his knowledge and experience of fatigue.

In Hazzard and Captain America's narratives, and by contrast with the girls' narratives above, mothers were presented as not expecting and even actively exempting the male adolescents from conforming to boys' gender expectations within the Ghanaian culture. Boys are expected to demonstrate physical strength, virility, competitiveness, and aggression, and young males typically learn and demonstrate these culturally-expected characteristics through sports and peer interactions (Nukunya, 2003). Despite presenting their mothers' expectations and actions as restrictive and interfering, Hazzard and Captain America understood and interpreted them as protective, a common perspective held by the boys in the study. According to them, maternal restrictions on their physical activities aimed to protect them from SCD-related consequences. Thus, SCD and its symptoms strongly influenced mothers' (lowered) expectations of the participants' 'maleness'.

One point to note here is that some of the boys reported having assigned duties at home under certain family circumstances (no female children, female children too young to do chores and less-resourced families). For example, Hazzard said:



**Figure 5.** "My favourite sport is football and Chelsea FC is my favourite team" (Captain America).



**Figure 6.** Captain America's computer.

I fetch water for the house and wash utensils. They are very tiring work for me. You see the poly-tank over there, that's where I fetch the water from every morning, but it's very tiring for me, so, most times I only fetch one bucket, and my mum continues. When I complain I'm tired, she tells me to go and rest.

Here, Hazzard reported doing some housework. Nevertheless, his account is different from the girls' accounts in that he conveyed having control and flexibility to carry out his chores when he feels able. In contrast to the girls' mothers' reported lack of understanding and support, he talks of his mother stepping in to help if he is tired. This contrast could be explained by the limited cultural expectations for males regarding domestic chores and the resulting lack of societal expectations of mothers to engage their sons in housework. In addition, Hazzard acknowledges that his mother shows understanding when he struggles, encouraging him to rest when tired. This was a common experience related by the boys with house chores, with mothers being presented as supportive during housework as compared with the girls.

### ***The implications of parental care, constraints and expectations***

Within the adolescents' accounts, the maternal expectations, constraints and care they experienced were described as having implications for their social status, sense of self, and ability to pursue independence and self-care. We will again look first at the girls' accounts, followed by the boys.

### ***Social status***

For the girls, strict maternal expectations and unsupportive attitudes were perceived as encouraging stigma and lowering their status at home. For example, Gandhi (aged 14, metropolitan area) said:

The way my mum treats me makes me very sad. Because I can't go about my house chores the way she expects, she thinks I'm lazy and continually compare me to my younger sister. She's made everyone in the house see me as lazy. When I go out, people treat me badly

because I've sickle cell, and when I come home, they also treat me badly because they think I'm lazy. I feel so alone. It's like I don't belong anywhere.

Gandhi reports feeling distressed about her mother's strict expectations and negative reactions toward her limitations. She talks about feeling lonely, singled out, and frequently compared to her healthy sister's domestic performance. She indicates how her mother's disabling responses and labelling of her performance as laziness (a motivated and, therefore, deviant behaviour) has led to a similar disabling attitude from other family members. This sense that mothers' strict expectations and inability to understand the disabling effects of fatigue led to feelings of stigma and tensions in their relationships at home was a common theme in the girls' accounts. With girls traditionally having a lower social status attached to their gendered performance in Ghanaian homes, this was felt to reduce their social status within the family further.

Gandhi's excerpt above also emphasizes the experience of double stigma (Turan et al., 2019): being stigmatized at home by being perceived as 'lazy' and stigmatized for her illness in the community. Double stigma is a concept used to characterize the convergence of multiple stigmatized identities within a person (Turan et al., 2019). In Gandhi's account, the experience of double stigma in the family and public domains makes her feel lost, neither belonging at home nor in the community. In response to mothers' disabling reactions, the girls frequently described their approach of pushing their bodies to present an appearance and performance congruent to maternal expectations. Mascara Lady (aged 13, suburban area) describes this below:

When my mum is angry with me, it makes me sad, so I try to do things the way she wants even if I'm tired, even when it leads to bad pains.

Mascara Lady seems to blame herself for her mothers' disabling responses towards her inability to meet expectations. As a result, she tries to minimize the effects of her limitations on her mothers' feelings and on their interactions and relationships. She achieves this by pushing herself despite the health consequences. Mascara Lady can be seen as engaged in 'hidden labour' (Scully 2010, p. 13), and with this process, she tries to salvage a credible identity and status for herself.

### *Sense of self*

Strict maternal expectations and disabling responses had implications also for the girls' view of themselves and their expected roles. For instance, Gandhi said:

My mum always reminds me that a girl should be swift and industrious about her domestic duties. What she demands of me and how she treats me makes me wonder what my family will be like when I grow up and marry. Can I become a capable wife and mother like my mum? I doubt.

Here, Gandhi speaks of her mother's sermon on the cultural expectations and duties related to gender. Gandhi seems to have used this alongside her mother's strict expectations and disabling responses as a yardstick to assess her capabilities in meeting gendered responsibilities. Failure to meet this standard has reinforced her sense of difference. She expresses doubt about being able to be 'industrious' in her future role as a mother and wife. While adolescents of both sexes with SCD are reported to have reservations and fear regarding future prospects due to SCD symptoms (Poku et al., 2020), for girls, their

experience of strict maternal expectations, associated demands and disabling responses seems to deepen their concerns and feelings of inadequacy relative to other girls.

In the boys' accounts, maternal restrictions and lowered expectations also deepened their sense of difference and feelings of inadequacy relative to other boys. However, these manifested in different ways. Joe Mettle's (aged 16, metropolitan area) and Hazzard's accounts are examples:

It hurts that I'm not able to participate in sports and play with my friends because of this stupid disease. It makes me angry with everyone, everything, and myself. What kind of life is this! I'm always indoors and alone. I can't play football. I can't be with my friends because my mum doesn't want me out there playing with my friends. I can't go on school trips. I literally can't do anything that every normal boy does (Joe Mettle).

My parents create unnecessary interference and resistance. They are not giving me a chance to be with my friends and play football with them. What is wrong with me wanting to be with them and be like them. And it's all because of my tiredness and the pains I get when I get very tired (Hazzard).

Joe Mettle and Hazzard see maternal (parental) expectations and constraints as barriers to desired 'normal' boy presentation. It heightens their sense of difference, making them more distressed and frustrated about their illness and limitations. The dominant masculine discourse in Ghana of physical and emotional strength, competitiveness and aggression create a narrow avenue to develop an identity consistent with masculinity. For adolescents with SCD, striving to conform to expectations within their social domains is an important aspect of their daily lives with their illness (Poku et al., 2018; 2020). Therefore, while SCD symptoms threaten the male adolescents' sense of 'normality' and their ability to pass as 'normal' (Poku et al., 2020), maternal *restrictions*, rather than maternal demands, pose an additional obstacle to 'normality'.

### *Independence and self-care*

Aside from the constraints threatening the male adolescents' social engagement and sense of 'normality', they also threaten their ability to pursue independence and learn and practise self-care. For example, Barca (aged 14, suburban area) said:

When I play every 15 min, I need to take 15 min of rest. Running makes me tired early, so I don't run until I get the ball when I'm playing football. This helps me be able to play for 15 min before needing to rest. But my mother has told my sports master not to let me play again. They shouldn't restrict me. At first, I couldn't even play for 5 min without rest. But gradually, my tolerance increased, and now I can play for 15 min. My friends know that I get tired easily. They all question my tiredness, I just tell them I get tired easily, but I haven't told them about my sickle cell. When I'm playing with them and get tired, I just excuse myself and rest. They don't complain about it. If they need to find someone to play my position, they do or play by themselves. Sometimes too, they stop the game altogether.

Barca demonstrates the importance of experiential knowledge to understand and live with SCD and its symptoms in this extract. He explains how engagement in leisure activities with peers has helped him to understand his performance capacity. He relies on this knowledge to learn, develop and negotiate self-care practices. He also illustrates his confidence in managing peer expectations and reports receiving support from his friends during interactions. Barca's account demonstrates the 'normal' transition process

where adolescents develop the skills and confidence for self-care and become responsible for their own behaviour and actions as they move to adulthood (Pals et al., 2020). Maternal restrictions and constraints can disrupt this 'normal' transition process, the development of independence, and the ability to develop self-care skills and practices.

## Conclusion

This is the first study to highlight, from the perspectives of adolescents with SCD in Ghana, how the parental role of caring for and socializing a child with SCD is influenced by the expectations associated with the sex of the child and the attached cultural gender norms. Noteworthy is that mothers featured predominantly in the adolescents' narratives about parental care, expectations and constraints, whereas fathers were largely absent. This resonates with existing literature which has suggested that fathers leave caregiving and socialization of a child with SCD to mothers (Atkin & Ahmad, 2000; Burnes et al., 2008; Berghs et al., 2020). Our findings have highlighted how adolescents with SCD perceive their mothers as interpreting the significance of SCD for them based on the cultural norms associated with gender roles, emphasizing the binary representations of gender in Ghana and demonstrating how it filters into the lives of adolescents with SCD. The girls described experiencing their mothers as more demanding and less nurturing because mothers prioritized their ability to conform to gendered expectations over their illness and limitations. By contrast, the boys presented their mothers as more protective and nurturing, prioritizing their illness over meeting gendered expectations, although they sometimes experience this as restrictive. This supports findings from previous research where African-American mothers talked about being more protective of their sons with SCD than mothers of girls with SCD due to their construction and interpretation of both cultural (gender) and racial expectations (Hill & Zimmerman, 1995). However, our study differs from previous work in that it presents adolescents' perspectives on parenting and their views on the implications for their health, identity and self-concept.

Our analysis also shows that maternal expectations are experienced differently by girls and boys. Girls primarily experienced maternal expectations as demands, whereas the boys experienced them as constraints. For all the young people in our sample, our findings also illustrate how, from their perspectives, maternal decisions and actions when negotiating care in parenting a child with chronic illness can worsen illness experience and disrupt the transition to adulthood. The tension between care and socialization based on gendered cultural expectations can affect the child's social status, sense of self, and ability to pursue independence and self-care.

This study has a small sample size in common with much qualitative research. A further limitation is that it focuses only on adolescents' accounts of parenting. Therefore, the findings need to be considered against the general teenage drive to assert independence and autonomy. Parents' own accounts may add different perspectives to this analysis. However, we note the similarity with Hill and Zimmerman's (1995) findings grounded in mothers' perspectives. Despite its limitations, this study contributes to the literature by highlighting how caring for a child with SCD is related to and extends parental socialization work. Culturally-mediated gender expectations that shape socialization norms also influence care. Our data clearly illustrate the pervasive

ways in which the cultural expectations linked to gender norms influence how mothers define, interpret, and manage their child's illness.

These dynamics of parental care have implications for health professionals who work with children with chronic illness and their parents/families. To date, interventions for children and their parents/families have mainly focused on the care practices needed to achieve optimum health outcomes. Most interventions target children's and parents' attitudes towards care practices, with little consideration given to the influence of gendered expectations of both children and parents. Therefore, we suggest that health professionals consider how cultural expectations in relation to gender may influence care practices.

## Notes

1. With the interviews observed by mothers, one was with a 14-year-old male and the other was with a 17-year-old female. The presence of the mothers did not appear to hinder the participants' stories as both participants were able to narrate the relational tensions between them and their parents.
2. The adolescents chose their own pseudonyms for anonymising their data.
3. Permission was sought from the young people and their parents to keep and use participant-produced images anonymously for research dissemination, in line with the ethical conditions.

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