

# Fatigue in Sickle Cell Disease: The Significance of an 'Orphaned' Symptom

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**4<sup>th</sup>**  
Global Congress

**Sickle Cell  
Disease**

In-person  
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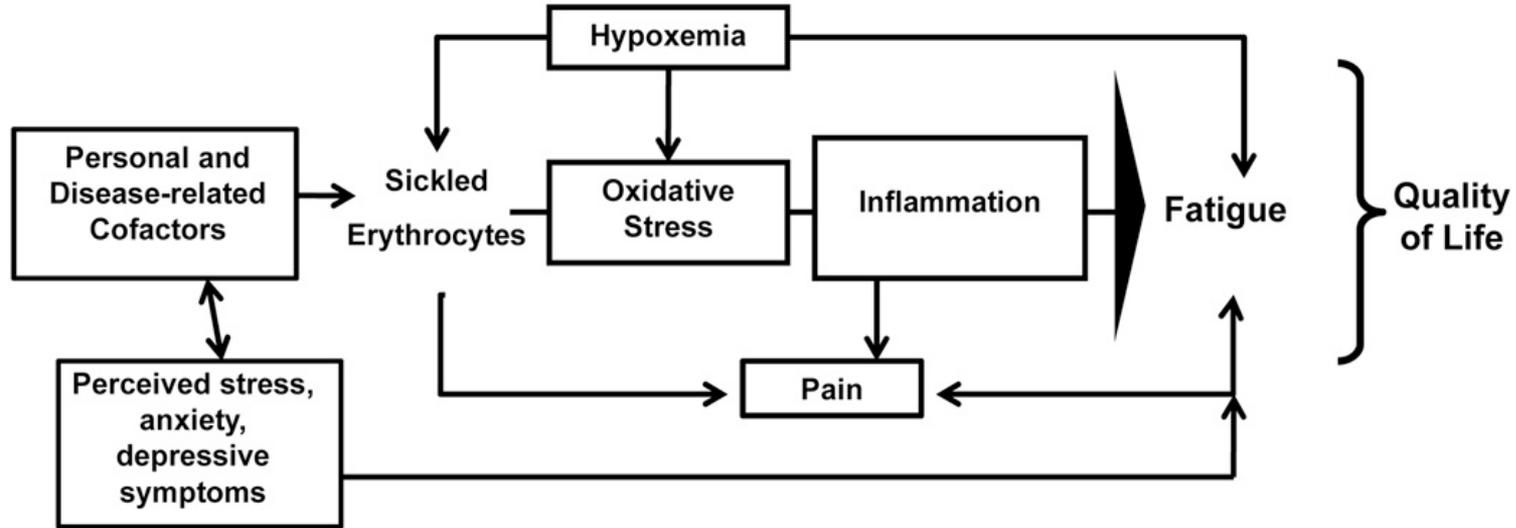


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# Biological and Behavioural Factors



(Ameringer & Smith, 2011)

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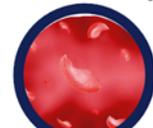
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# Potential Impact of Fatigue

- Poorer quality of life
- Increased episodes of acute pains
- Depression & anxiety
- Behavioural problems
- Reduced cognitive functioning
- Increased hospitalisation rates
- Missed school & work days
- Missed caregiver workdays



Adolescents' experiences of living with sickle cell disease: An integrative narrative review of the literature



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## ARTICLE INFO

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## ABSTRACT

**Background:** Sickle Cell Disease is the commonest monogenic haemoglobinopathy worldwide. Living with a long-term condition such as sickle cell disease during adolescence constitutes a significant challenge for the key stakeholders due to the combined effects of chronic illness and adolescent development. For adolescents with sickle cell disease to be cared for and supported appropriately and effectively, it is crucial that health professionals have a comprehensive knowledge and understanding of how adolescents experience living with the condition. While there is developing literature about how adolescent's experience sickle cell disease, this body of research has not been critically reviewed and synthesised.

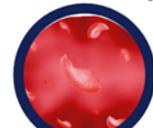


# Meaning of Sickle Cell-Related Fatigue

- Fatigue: *a feeling of being extremely tired, usually because of hard work or exercise* (Oxford Learner's Dictionary)
- Ever-present, low-grade and becomes severe with activities of daily living (physical and social)

I feel tired everyday. I sometimes wake up already tired no matter how well I have slept. Being tired is like a routine, it only gets worse when I actively engage in physical activity  
(YPF1, aged 13)

Me, I'm always tired, even when I've not done anything because my energy is always short. So, when I do things like walking, the tiredness becomes worse. I sort of always feel weak  
(YPF7, aged 15)

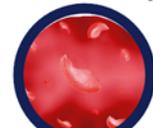


# Meaning of Sickle Cell-Related Fatigue

- Multidimensional in nature – physical, emotional, cognitive/mental, social, personality/behavioural, sensory

I feel **angry**. I **can't concentrate** and I **easily forget** things. I become **dull** and I feel **exhausted**. It makes me ignore everything around me and I become **unfriendly**. Everything said to me sound like nonsense. I feel like I need to **lie down**. I **sweat** and I feel **dizzy**. In my body, I feel like I've been **beaten up**. I stagger if I'm walking. When I'm tired, I **change completely**. My facial expression become **uninspiring**. It makes me **miserable!** (YPF1, aged 13)

The feeling of tiredness is very **horrible**. It's like being pinned down by a wicked macho man, and **you can't do anything or free yourself** from him. **You can't fight it, so you give up and lie down**. If you fight it, you'll end up with a **bad crisis or worse collapse**. It's happened to me before (YPF 10, aged 13)



# Meaning of Sickle Cell-Related Fatigue



It's [tiredness] like a car with no petrol. Nothing will make it move. You just have to park. It'll only move when you put petrol into it. Me too when I'm tired, I can't do anything because I have no energy for anything. (YPM4, aged 14)



It's [tiredness] like a dead battery with no a capacity of zero. There's no energy for anything. Not even to keep my eyes open. (YPM12, aged 16)

My body is like a 64MB pen drive. It mean that it has a vey little energy capacity due to my sickle cell. Therefore, it [energy] get used up very fast. I never have enough for the things I want and need to do (YPM11, aged 16)



# Meaning of Sickle Cell-Related Fatigue

- Fatigue is an inextricable part of day-to-day activities



Everyday activities use up my limited energy: sweeping, cleaning, washing dishes and clothes, running errands, school work, running and playing games with my friends. I feel exhausted even from carrying my schoolbag, when I walk a short distance or go up a few steps up a stair or sit or stand for a while (YPPF21, aged 17)

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# Contributory Factors

- Socio-cultural expectations of youthfulness – fatigue is antithetical to youthfulness
- Racial stereotypes – “black athleticism” and the “strong black woman/girl” narratives
- Racism – experiencing and resisting racism

In the house, in school and among my friends, it's like **you're not supposed to complain that you're tired** when everybody isn't. It's like if you do something small and you say you're tired, it means you don't want to do it or you're lazy. They make it sound like you've decided to be tired. **They don't believe you** because how can you be tired when you've almost done nothing and when **you're not an old person** who is weak and frail. They see you as normal, you know, **you're not disabled** so why should you get tired easily or why can't you do this or that. When someone meets you, **they can't tell you get tired easily, so they expect you to be normal**. So, I tend to force my self even when I'm tired to avoid being called a lazy girl. As you know when you push yourself, you shut down eventually. (YPF6, aged 13)



# Everyday Impact of Fatigue

- Barrier to social, educational, employment and family participation
- Restrict biographical presentations, sense of identity and normality
- Stigmatising consequences - labelled as lazy, weak, 'not black enough'

when I'm with my friends and playing football, I don't want to disappoint the team, the rest count on me to play my position. When you commit yourself to something, you've to make sure you complete it. **If you disappoint them, they'll never let me play again**, so I'm must show they can constantly rely on me. (YPM7, aged 14)

It [tiredness] me feel bad because he [friend] **tease me that I'm weak, girly, and there's no fun playing with me** because I'm always complaining that I'm tired (YPM8, aged 14)

Research Article

## **"Body as a Machine": How Adolescents With Sickle Cell Disease Construct Their Fatigue Experiences**

Brenda Agyeiwaa Poku<sup>1</sup>, Ann-Louise Caress<sup>2</sup>, and Susan Kirk<sup>3</sup>

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# Everyday Impact of Fatigue

SOCIOLOGY OF HEALTH & ILLNESS

ORIGINAL ARTICLE

- Pain experience
- Social withdrawal and isolation

Biographical accounts of the impact of fatigue  
in young people with sickle cell disease

Brenda Agyeiwaa Poku  | Alison Pilnick 

I have had whole-body tiredness that led to a **severe painful crisis**. In 2015, I came home from school; I was very tired ...so I came home in a taxi. I went to rest and I feel asleep. When I woke up, I couldn't walk. I was **hospitalised for 2 months 2 weeks**. I **missed the school whole term**. That whole-body tiredness is what I'm scared of everyday, but it's so hard to avoid it with everything I'm expected to do. I have realised that I can't be like my peers and friends no matter how hard I push myself. So, I have decided to **cut down on spending time with my friends and engaging less in physically-demanding activities with them**. I **keep to myself most times**. But it's hard and sad to accept this and not want to be like others or not want others to see you as normal. (YPM12, aged 16)

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# Everyday Impact of Fatigue

- Educational, academic, career and professional choices
- Perceptions of future lives and roles

ORIGINAL ARTICLE

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I think marriage and kids are things I can't have when I think of the responsibilities involved and my limited energy level. It'll not be easy for me combining career, marriage and motherhood.

They are all energy-demanding,. It'll be overwhelming! (YPF15, aged 17)

We've to go by our energy limits, so we need to choose jobs within our energy limits to take care of our families in the future. That's why I wan to be an architect. I've chosen architecture because of my energy level. We don't have the strength and therefore can't do any work. We need to consider our energy limits (YPF14, aged 16)

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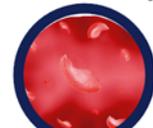
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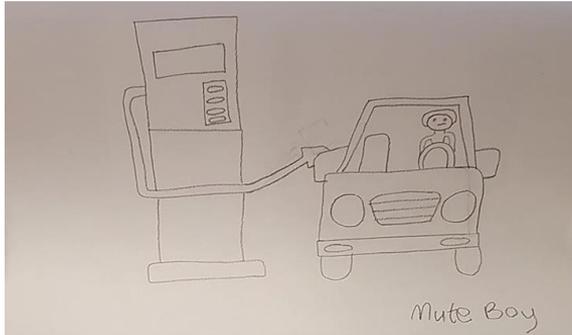
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# Coping with Fatigue

- Social withdrawal and self-isolation
- Adequate nutrition and hydration



I **drink water and rest when I get tired**. It's like daddy going to the petrol station to get some petrol in the car when it gets finished (YPM24, aged 12)

My tiredness holds me back from being with my friends because being with them is physically demanding. I **mostly avoid being with them** or playing with them to avoid getting tired (YPM14, aged 16)



# Coping with Fatigue

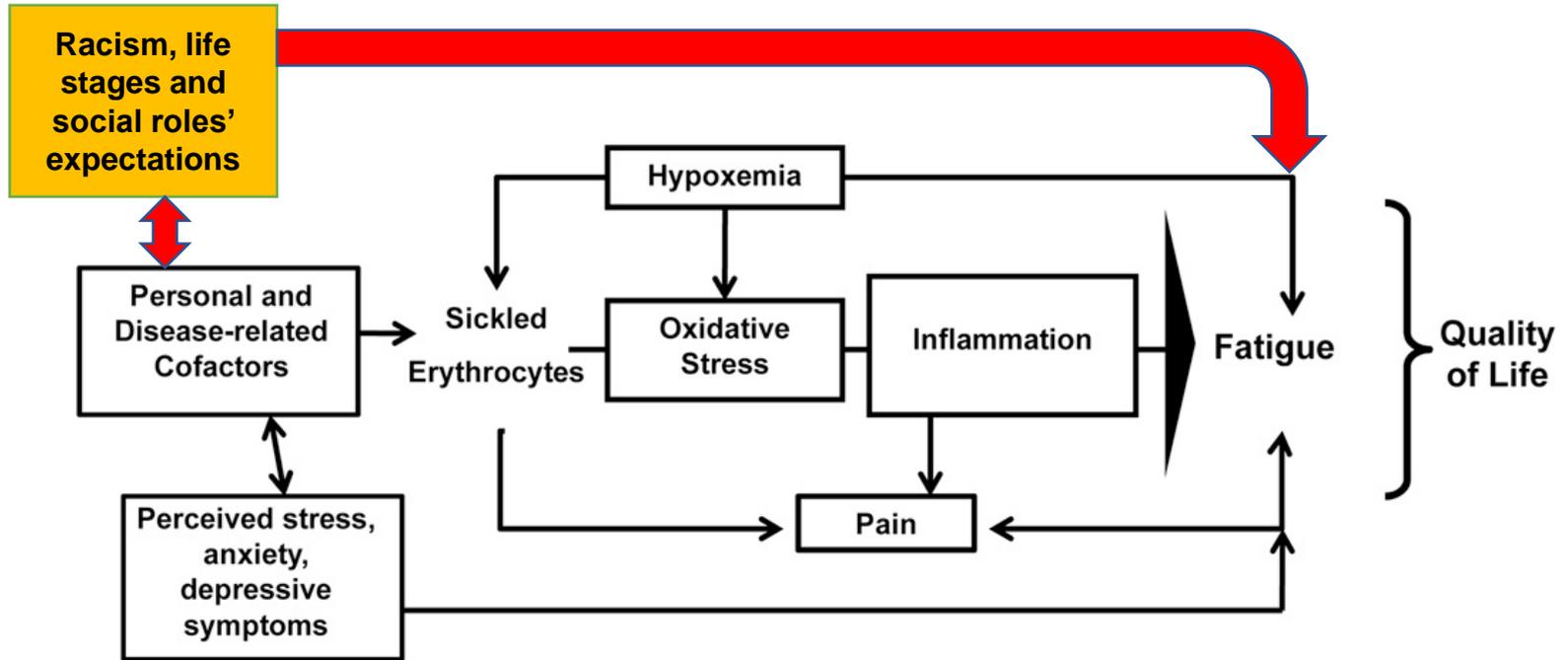
- Little or no support from others

When you have people always looking at what you do and how you do things, it's hard to do things that would help you prevent tiredness. **They don't understand you.** So, if you're resting regularly, doing things slowly, or avoiding certain things because you don't want to get tired, **they see it differently**, like you're doing all that because **you're lazy or weak or you're just making excuses.** So, I usually avoid people and just be on my own (YPF17, aged 14)

One time, I complained to my doctor about it [tiredness] but **all he said was that it's part of it [sickle cell] so rest when you feel tired and don't stress yourself too much.** For me, tiredness brings the pain, but when I report to the hospital with pains, **they just sort it [pain] out; they don't bother to ask about what triggered it.** So, I don't talk or complain about it [tiredness] anymore. **I just deal with it** and hope it cause the pains (YPF14, aged 17)



# Model of Sickle Cell-Related Fatigue



# Conclusion

- Fatigue is the most restrictive and disruptive aspect of living with SCD
- It's an inescapable part of daily life and closely linked with daily activities
- It's both a medical and social symptom that impact life decisions, choices and outlook
- Overlooking fatigue in care, research and advocacy work is synonymous to ignoring an important aspect of improving quality of life
- **First step: acknowledge the significance and legitimacy of fatigue in care, research and advocacy work**

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