

# Self-Reported Experiences Living with Sickle Cell Disease in Ghana: Implications for Occupational Therapy



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## Introduction

Occupational therapy (OT) is an emerging practice in Ghana. Between 20-30% of Ghana's population experience Sickle Cell Disease (SCD) (WHO, 2015). SCD causes inadequate distribution of oxygen throughout the bloodstream. Chronic pain, fatigue, and immobility from SCD can interfere with major aspects of life including: education, employment, and psychosocial development (WHO, 2015).



## Methods

Phenomenological approach with 5 adults living with SCD in Kumasi, Ghana. 5 semi-structured interviews per participant. 1 observation of occupational performance per participant in the home or workplace. Semi-structured interviews of 5 healthcare practitioners.

## Purpose

To determine how OT could benefit the well-being and quality of life for individuals living with SCD in Ghana.

## Questions

## Findings

## Quotations

### Beliefs about SCD

Etiology  
Stigma  
Spiritual beliefs

- "They say sickle cell- that it's sickling- the blood clots somewhere and I will feel some pains there, that's all." (Akosua)
- "I'm not sociable because of the sickle cell. I don't like going out with friends ... because they can do hard and you can't do it; so sometimes they think you are lazy- it's not like that." (Abena)
- "They don't allow me to do certain things I am able to do, a small thing- they say don't do it, you're a sickler." (Kwasi)
- "My sisters, they dislike me. They say, maybe, I'm not a child of their father because I'm living with sickle cell." (Akosua)
- "Even the pains, they will say you are a witch because you are always getting sick." (Adwoa)

### How SCD affects occupations in Ghanaian culture

Education  
Social participation  
Sleep  
Self care  
IADL  
Employment

- "Sometimes I need to do something for myself which I can't do because of my problem... I wish I graduated but because of my health I couldn't continue my school." (Abena)
- "People see you have sickle cell, they excluding you from activities. You feel like you are not part of the world." (Kwasi)
- "Whenever you sleep ...you have the pain in your joint so ... you have to lie down and position yourself so you don't have that." (Kwadwo)
- "With the sickle cell, if I have pains I don't try to take my bath at all." (Adwoa)
- "At first I used to take care of my grandchildren but because of this thing, the sickness, they went to their mother's place." (Akosua)
- "What I wanted to do in life is not what I'm doing now." (Adwoa)

### Adaptations for engagement in occupations

Breaks and rest  
Assistance from others  
Pain management  
Few modified tasks  
Assistive device (only 1)

- "I was a seamstress, but anytime I sit down for a long time, then I feel some pains and I have to stop." (Akosua).
- "When I am in crisis I need help from other people. To help me go to school, to help me go buy drugs, give me meals, take me to the hospital, assist me lifting a load or something. Apart from that I don't need any assistance." (Kwasi)
- "Sometimes I just hold my veins to stop that from filling where I am feeling the pain." (Kwasi)
- "I have to organize everything here [beading sandals] so I don't get up and I will sit down." (Abena)
- "I use all the electrical kitchen gadgets that I can use. So I can make everything easier." (Adwoa)

### Awareness and openness to OT services

Patients & Practitioners  
Limited awareness  
Open to services

- "We are as the normal woman is. We can do it; We can do it. I'm a sickle cell patient. I'm living, so why do we think we will die, we won't die." (Abena)
- "Because of their condition, sometimes they are in pain and if measures like occupational therapy are brought to make them do certain things without pain or do certain things that they would enjoy, then it would be beneficial." (Nurse)
- "I think it's a great thing ...you [OT] look at all the triggers, what triggers the kind of crisis they have and then you try to modify the environment, whether it is home or school or whatever, to suit them." (Doctor)

## Participants

Name (pseudonym)	Gender (M/F)	Age (yrs.)	Occupation (primary)
Abena	F	45	Trader
Adwoa	F	40	Chef
Akosua	F	61	Seamstress
Kwasi	M	19	Student
Kwadwo	M	27	TV-Mechanic

## Discussion

Participants experienced stigma because of SCD  
↓  
SCD affects all areas of life  
↓  
Participants reported resting and relying on others  
↓  
Potentially reinforced stigma  
↓  
Few reported task modification or use of assistive devices

## Implications

Suggest modification and assistive technology  
↓  
Promote greater independence  
↓  
Promote participation in desired activities  
↓  
Decrease stigma  
↓  
Benefit well being and quality of life

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