

SICKLE CELL AND THE PSYCHOLOGICAL IMPACTS OF MEDICAL NEGLIGENCE AND IATROGENESIS

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Race on the Agenda

Acknowledgments

We would like to extend our deepest gratitude to Xaira Olaifa-Adebayo for her crucial work in producing this important and timely piece of research, and for her dedication and hard work throughout the second year of the ROTA Community Research Partnership (RCRP).

We are equally grateful to all members of the second-year RCRP cohort for fostering such a dynamic, supportive, and collaborative research environment.

Finally, we extend our sincere thanks to everyone at City Bridge Trust and Propel, whose support has made this work possible.

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EXECUTIVE SUMMARY

Sickle Cell Disease (SCD) is a serious, lifelong genetic condition that primarily affects people of African and Caribbean heritage. Xaira's research examines how systemic racism, racial bias, and institutional neglect can converge to produce iatrogenic harm—which is caused or compounded by healthcare itself resulting in deep and lasting psychological trauma alongside physical suffering.

From the dismissal and minimisation of pain to traumatic procedures and inadequate or inaccessible mental health support, the research brings attention to experiences in which patients can feel unheard, retraumatised, and ultimately abandoned by the healthcare system intended to care for them. This research is particularly important because awareness of SCD and the experiences of those living with it is growing, both within BGM communities and beyond. Yet awareness alone does not necessarily translate into the services that are adequately responsive to the pain experienced by patients.

SCD is the most common genetic disorders in the UK, yet it remains hugely under-researched and under-funded. That is why Xaira's research is integral it moves these experiences beyond individual moments of visibility. By documenting and examining lived experiences in a structured way, it contributes to a deeper understanding of the relationship between healthcare, racism, medical trauma, and psychological harm. It also demonstrates why community-led research is so important: it creates space for communities to tell their own stories, identify the issues that matter to them, and generate knowledge that can contribute to lasting change.

We hope this research prompts not only greater awareness but that is also serves as a reflection and action. must change to ensure that seeking care does not itself become a source of further harm.

The key recommendations are as follows:

- 1. Integrate Mandatory Mental Health Screening & Support:** Implement routine psychological and neurocognitive assessments within comprehensive SCD clinics. Fund and embed culturally competent therapists within haematology teams.
- 2. Enforce Anti-Racist, Bias-Aware Clinical Training:** Mandate ongoing training for all staff on racial bias in pain perception, deconstructing “drug-seeking” stereotypes, and trauma-informed communication. Link training to professional revalidation.
- 3. Overhaul Accountability & Redress Mechanisms:** Create an accessible, independent reporting and investigation system for SCD patients experiencing negligence. Ensure complaints lead to transparent, meaningful change, not generic letters.
- 4. Fund & Legitimise Peer-Led Community Support:** Allocate NHS funding to SCD community support groups, recognising them as essential, evidence-based components of care that provide validation and belonging absent from clinical settings.
- 5. Mandate Proactive, Coordinated Care Pathways:** Legally enforce the use of Individual Care Plans (ICPs). Establish formal, accountable multi-disciplinary teams (MDTs) that include mental health professionals. Implement strict escalation protocols for patient concerns.

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Sickle Cell Disease (SCD) is an inherited haemoglobinopathy characterised by acute, severe pain episodes caused by vaso-occlusion. The disease can lead to physical challenges such as progressive organ damage and psychosocial challenges (Franco, Gonzalez, McGirr-Crowley et al, 2024) (Ware, R. E., de Montalembert, M., Tshilolo, L., & Abboud, M. R. (2017)). SCD primarily affects people with African or Caribbean heritage; thus, race as an intersectional frame of analysis is warranted when trying to understand the treatment of people with SCD in the NHS. Reports by Public Policy groups, such as the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG), have responded to the recent rise of cases of medical negligence and substandard care towards sickle cell patients.

The report, largely filled with oral testimonies, documented the pervasive role of racism in substandard care for people with SCD. Likewise, themes such as inadequate knowledge of SCD by healthcare professionals, social stigma, lack of compassion and racialised biases towards pain management have been prevalent in research and reports completed over the past 30 years, which have recorded first-hand testimonies from SCD patients and carers. Longitudinal qualitative studies, such as those by Renedo et al., have highlighted the importance of producing research that emphasises the need to move beyond individual models of treatment for SCD to improve healthcare experiences, and instead integrates critical models of medical sociology that recognise the challenges people with SCD experience.

1. BACKGROUND

Evan Nathan Smith, 21, contracted sepsis after a gallbladder surgery, which triggered a sickle cell crisis. Evan died as a result of multiple organ dysfunction as a result of a sickle cell crisis caused by sepsis. The coroner, Dr Andrew Walker, concluded that the cause of Smith's death was a delay in treating him with a "timely exchange transfusion" and a "lack of understanding of sickle cell disease in the medical and nursing staff looking after Mr Smith (Guardian, 2019). Smith's case is not an isolated incident and has been ruled as a form of iatrogenic harm via medical negligence.

Iatrogenesis describes harm resulting from the actions of health care professionals, including but not limited to "side effects and risks associated with the medical intervention. (RF, Shabir N, 2018; 7(2):309-314). Although iatrogenesis tends to describe the harm precipitated by particular health care practitioners, there are also structural forms of bias and inequity that contribute to medically induced harm. (Tao and Ksumi Clements, 2022, Vol 24. No. 8). The majority of observational and interventional studies on Sickle Cell and institutional neglect have been conducted in the United States, with funding still suboptimal in the UK. Between 2010 and 2023, a total of 387 projects were awarded by NIHR, UKRI and Wellcome for inherited genetic disorders; 19.4% went towards SCD. Contributing to this growing body of literature, this chapter focuses on the structural biases and practices that underpin iatrogenic harm and the long-term psychological effects of these events. Centring participatory action research, the report underscores the necessity of mental health screening as part of a multi-modal and multi-disciplinary approach to create and operationalise patient-centred care for people with Sickle Cell.

2. METHODOLOGY

The initial methodology for this study was a mixed-methods approach, with an initial survey circulated through personal networks; however, responses were sparse and fragmented. Thus, a qualitative study utilising semi-structured interviews was adopted later on. Participants were recruited via electronic flyers distributed through social media platforms and, later, in person at sickle cell conferences and sickle cell support groups. The sample included individuals ranging from the ages of 24 to 53 living with SCD and were ethnically mixed between Black Caribbean and Black African. There were six female participants and one male participant. Participants were compensated for their time. In order to promote anonymity, participants are not named in this report. Interview transcripts were thematically coded in NVivo.

3. RESULTS

3.1 GENERAL EXPERIENCE WITH PRIMARY AND SECONDARY HEALTHCARE

This section investigates the underlying structures and attitudes to adverse events (iatrogenic harm). These events are not isolated but the result of compounding forms of negligence, dismissive attitudes, and racial bias that promote inequitable standards of care.

3.1.1 EMERGENCY SERVICES, GP PRACTICES AND LACK OF URGENCY

Participants were asked to describe their overall experience with the healthcare system as sickle cell patients. Prolonged waiting times, delayed intervention, failure to escalate and a pervasive sense of being deprioritised within primary and secondary care settings were prominent sub-themes of their responses. The average waiting time for participants to be admitted to A&E during an acute sickle cell crisis was 4 hours, whilst drug admission time was 3.5 hours after checking into A&E, despite NICE Guidelines recommending that analgesia should be administered within the first 30 minutes of admission. This often led some participants to use the A and E as a last resort when experiencing acute sickle cell crises. One participant noted that they *"avoid going to the A&E, they have us waiting for long periods in excruciating pain"*. While another participant noted that *"waiting time for me takes more than 4 hours, in regards to getting medication, I usually need to ask about 5 times or more."*

Further, negligence and a dismissal of the urgency of care within GP practices were cited frequently by participants, with 57% reporting some negative experience with their GP. Participants described their experiences with their GPs as misinformed, lacking sympathy, and rushed. One participant recounted a particular experience where the GP refused to complete any basic checks required for sickle cell patients and told them *"to go to the A&E"* for any concerns, despite expressing discomfort and pain. Elaborating on how this encounter made them feel, the participant noted that *"it seemed like overall she didn't believe me, and it was quite cold... most of the issues I have had with accessing health care are with the GP practice."*

3.1.2 CROSS-DISCIPLINARY COMMUNICATION AND DOCUMENTATION HANDLING

Communication and documentation handling between primary care and other tiers of health care has been noted as a source of iatrogenic harm. Three participants highlighted that complicated surgeries were inappropriately handled due to insufficient communication between healthcare teams, including the GP and specialists, and the Haematology department. Participants mentioned poor co-ordination across multi-disciplinary teams, with one participant stating that *"sometimes you have to be the middle man, you have got to be pushing for it; my gastrologist prescribed me some medication and I didn't receive it until I went to the general ward 3 to 4 weeks later, the delay occurred as they had assumed that the haematologist would prescribe it, which wasn't the case."*

The failure to comply with ICP's (Individualised care plans), a healthcare plan often developed in collaboration with the patient and their haematologist that documents an individual's SCD history and tailored recommendations for management of APCs (acute pain crisis), was highlighted by participants as a recurring issue, leading to delays for appropriate treatment. Issues with adherence and implementation of ICPs have been documented in other reports, such as *"No one is listening"*, which highlighted the failure of compliance by medical staff. One participant highlighted that *"I would have to argue with doctors about how much blood I am supposed to receive, they would refuse to look at my notes... I have had to fight for them to read my charts."*

Another participant recounted a particularly traumatic experience where they were nearly administered for a Kidney transplant, due to poor procedural compliance by hospital staff. *"They said I had surgery, and I protested against this, even though I was very drowsy from the drugs... no one was listening to me. When they finally checked my notes, they realised they had gotten the wrong patient and I wasn't due for a kidney transplant."*

3.1.3 FAILURE TO ESCALATE

95% of participants commented that the general sentiment towards people with Sickle Cell by healthcare professionals was dismissive, avoidant, and reactive. This attitude often led to a failure to escalate regarding concerns with organ damage and chronic everyday pain caused long term irreversible damage. Three participants highlighted that they were told to *"wait and see a couple of weeks or months"* when they brought up unusual, prolonged pain and growing concerns for their health. *"At the age of 18, I was diagnosed with vascular necrosis in my right hip.. I feel like the NHS could have picked that up sooner...When I initially complained about my right hip, the professionals said to go away and come back six weeks later, but this kept extending until it was months... It was only after many attempts of complaining about the pain that they did a scan to discover that the bone was dying.... I think doctors and my GP could have done a lot more regarding offering preventative treatments, hydrotherapy, more physio... after my hip replacement, I didn't get any bi-yearly review or any physio at all... There isn't a lot of support or care for us in comparison to other people with long-term health conditions."*

The improvement of coordinated care is a necessary recommendation to diminish iatrogenic harm, especially in joint clinics with renal physicians, pain-management teams, obstetricians, and cardiologists. It is essential to emphasise the extension of this coordination to extend towards one that takes mental health screening in a proactive methodology.

3.2 STIGMA AND BIAS IN PAIN AS A RACIAL MECHANISM IN CLINICAL ENCOUNTERS

Clinicians' racial biases can act as pathways for the imposition of iatrogenic harm and inequitable health outcomes of black people (van Ryn M., 2002). Racial disparities in adequate pain management are examples of the kinds of harms and inequities that these biases cause. Various studies have highlighted how the racialised biases in pain perception impact overall treatment. For example, Hoffman and Trawalter et al investigated the prevalence of false beliefs about black people's tolerance by white medical students and how white medical students often rated black patients' pain as lower than white patients (Hoffman KM, Trawalter S et al, 2016).

3.2.1 SKEPTICISM ABOUT PAIN

Participants consistently commented on the stigma that Sickle Cell comes with as a racialised chronic illness, with many concluding that racism was a key factor in their mistreatment and the perception of their pain. One participant has highlighted that the bias from clinicians has sometimes led to them not intervening until the last possible moment, *"What traumatised me is that if I didn't say that I had fainted or fallen out of my bed as a result of being in so much pain. Nobody would have done anything. I feel like I always have to fight for basic treatment."* Staff scepticism about pain. Another participant describes being left unattended in the bathroom during a crisis by a nurse who refused to believe their pain *"My shoulders were in so much pain... I couldn't raise my arm to the lever... She didn't believe this, and she decided to leave me there."*

3.2.2 SEEKING STEREOTYPES AND OPIOIDS

Opioids such as Morphine or Oxycodone are examples of analgesic treatment for APCs. Providing adequate pain control during severe episodes. However, stereotypes about black patients as 'drug seekers' and opioid dependent influences clinical practices in pain management. A study on the monitoring of patients on chronic opioid therapy highlighted how black patients were less likely to be referred to a pain specialist and more likely to be screened for substances and referred for substance use evaluation in comparison to their white counterparts. The study also commented on how some clinicians implicitly subscribed to the racially biased belief that black people exaggerated their pain and used deceitful practices to acquire opioids illicitly.

Participants highlighted how this perception of black patients impacted their treatment and often made crises unnecessarily painful due to a delay in further administration of drugs, due to scepticism. *"I have had to roll on the floor for extra pain medication... I remember having a chest of drawers crisis and getting out of bed and rolling, as I had been crying and screaming for extra medication for like an hour with the little breath that I had."* Another participant noted that *"I have had nurses say that I am addicted or drug-seeking, and I have had to fight for my pain relief. I have been in a particular situation where my pain relief is only understood by a particular nurse"*.

3.2.3 INTRAVENOUS CANNULATIONS, LOSS OF AUTONOMY AND EMOTIONAL SUPPRESSION AS A FORM OF IATROGENIC HARM

Intravenous cannulation, often a challenging procedure for those with SCD, due to recurring damage to the veins and irritation of the bloodstream for intravenous access, came up as a common site of iatrogenic harm. Four participants referred to Intravenous cannulations as an adverse event that generated long lasting psychological harm or immediate re-hospitalisation. One participant describes going in for a blood transfusion that ended badly due to issues with the cannula *"They couldn't find a vein and brought in loads of doctors jabbing my arms...I was supposed to be there for 2-3 hours. I ended up being at the hospital for a week after having a crisis due to blood clots formed during the procedure."*

Commenting on how they felt during this procedure, the participant recalled being *"very distressed and angry. I felt like my voice didn't matter, my sister tried to advocate for me, and no one was listening. The nurses were more compassionate than their colleagues. I felt like nothing. No matter how many times I told them to stop or get other professionals involved. It was excruciating"*.

Participants noted that they were not listened to during these processes and not involved in the decisions about how to manage their emotions and their bodies. The violation of patient autonomy can generate copious amounts of distress but also forms of emotional suppression. *"When I was in hospital, I had a strong phobia of needles, you tend to develop a strong aversion to them, I remember being woken up in the middle of the night by the anaesthetists and nurses, they pressured me to go through procedure and forced me to **suppress** the panic attack I was having at the time, even till this day, that occurrence has given me PTSD, if I am in a particular situation or stressed that incidence comes up as a recurring flashback."*

3.3 LONG TERM PSYCHOLOGICAL IMPACTS

Medical negligence can contribute and exacerbate pre-existing psychological conditions, but also generate new ones. When asked about their general mental health experience with SCD, many participants noted symptoms such as "depressive episodes and lots of anxiety" and general feelings of loneliness.

3.3.1 PTSD AND EMOTIONAL ALEXITHYMIA

Negligence in the form of inadequate monitoring of antibiotic treatments is even more concerning for patients with Sickle Cell, who become immunocompromised very easily. One participant received an insufficient duration of antibiotic treatment, which meant that the underlying infection progressed and developed into sepsis. This led to a near-death experience triggered by the sepsis-related sickle cell crisis and months of hospitalisation. After this adverse event, the participant noted that they had to get therapy due to experiencing bouts of PTSD, unwarranted flashbacks, and long depressive episodes associated with the adverse event. Thus, an example of how iatrogenic harm can lead to long-term psychological impacts.

Another popular sentiment was the inability to categorise how specific incidents made participants feel. Emotional alexithymia, a difficulty in expressing or identifying emotional distress as a result of compounding and ongoing trauma, was particularly evident among various participants. *"I don't know if I have processed it well... I am trying not to gaslight myself, like did this really happen or not?"* one participant said when recounting how they felt after they had been given a double dose of anaesthesia against their wishes.

An avoidance of certain health providers was noted as a short-term strategy to alleviate mental health symptoms such as anxiety. Further, participants reported delaying hospital admission when in acute sickle cell crises or avoiding care despite potential risk, thus demonstrating how iatrogenic harm can worsen health outcomes due to psychological effects. Other effects included hypervigilance and anticipatory anxiety when it came to complex procedures such as surgery, difficulty trusting healthcare staff and a reluctance to speak up when unsatisfied.

3.3.2 PROVISION OF MENTAL HEALTH SERVICES AND BARRIERS OF ACCESS

Sickle Cell, as a chronic illness, is complicated by mental health disorders such as depression and bereavement. Patients with chronic diseases are predisposed to psychiatric comorbidities. However, in the sickle cell disease (SCD) patient population, psychiatric comorbidities have been uniquely shown to exacerbate the disease through a psycho-somatic component. A co-existing diagnosis of depression is found in 1 of 3 patients with SCD, and they are more than 5 times more likely to suffer with a mood disorder than the general population (Phan, Dambala, Ilyas et al, 2023). Additionally, a study by Dirican et al (2025) highlights how pre-existing mental health conditions such as MDD (Depressive disorder) and anxiety elongated hospital stays for people with SCD. Thus, mental wellbeing is a crucial element of treatment for Sickle Cell patients.

One participant discussed in depth how other external life factors, such as the loss of a parent, impacted their physical health and how medical professionals often overlooked this. *"I would have a lot of crises after my mum died... I think a lot of it was caused by grief... but I was never given any psychological report or assistance to help cope, just hydroxyurea pushed onto me"*. The above testament provides an opportunity to invest more research and resources in understanding how mental health impacts the wellbeing of sickle cell patients and, more importantly, to screen sickle cell patients for pre-existing mental health conditions to develop a holistic, integrated care plan.

When it came to accessing mental health services in order to deal with the complexity of Sickle Cell as a chronic illness and post-iatrogenic harm treatment, many participants highlighted that this was not an option given as part of their health care plan. Mental health services were accessed mainly via other medical departments, highlighting the absence of an integrated psychological care within sickle cell treatment pathways. For example, the same participant commented on how they *"had therapy last year, but that was because of a car accident that I had.. and they recommended CBT. The CBT was about the accident, but I found that everything that had happened over the years was spilling out into the therapy session, i.e. I never had any bereavement when my mum died. I only had 10-12 sessions for the CBT."*

3.3.3 GENDERED INTERSECTIONS AND MODELS OF MENTAL WELLBEING FOR BLACK SICKLE CELL PATIENTS

Further, the experience of often being ignored, invisible, neglected and underprioritised seemed also to impact the level of action participants wanted to take in expressing further assistance with their mental wellbeing. This was particularly salient among black female participants. Feelings of helplessness were evident in some participants' responses. *"No one is going to be strong for me. So I have to do it for myself... it's not one battle... But it's continuous... There's never any break. I have to be strong for my own sanity. I don't have time to break down and cry as such. The only time I cry is in a crisis. I just have to keep going."*

The stereotype that black women were 'strong' and the expectation to 'deal with it' often meant that there was a lack of expectation that such women could experience mental distress and in turn, stopped them from seeking help. (Kalathil, J., 2011). Limited access to mental health support also deterred participants from seeking recovery from pre-existing psychological ailments or those generated through iatrogenic harm. *"I have never had mental health support. I have tried to get talk therapy, but because I am out of the catchment area, they said that there would be long waiting lists. Also many services have an age requirement of 18 and below. When I have tried to get different routes, I have always been turned down, and none of my healthcare professionals have helped me."*

The same participant describes the dismissive attitude from their GP concerning their mental wellbeing: "Even trying to get tests done or anxiety or depression at my GP, they have been dismissive of me. They have said, *"oh, you're fine... you're bubbly."*

In an investigation into the implicit bias present in healthcare practitioners in decision making concerning depression, it was found that primary care doctors in this study across the US and the UK had difficulties diagnosing depression with black patients. Further, it was proposed in the study that the pre-existing health conditions in black patients in both countries meant that doctors focused solely on physical conditions even though some diseases, for example cardiovascular diseases, are complicated and exacerbated by depression (Adams A., Vaila L., et al, 2014).

Overall the study highlighted how there was a greater uncertainty in the diagnosis of emotional problems and depression in black African and African Caribbean patients and the need for the development of a mental health model of a flexible mental health model of depression presentation in black patients. Similarly, with SCD, when patients attempt to receive mental health services to treat psychological effects of iatrogenic harm, this is dismissed by healthcare professionals or is structurally inaccessible. Thus, the perception of pain, whether it's physical or psychological, seems to be a precursor to the negligence of patients with SCD and simultaneously a probable cause of iatrogenic harm or the inability to treat the long-term psychological impacts appropriately.

3.4 BARRIERS TO REDRESS

When it came to taking action to report these experiences post-sickle cell crisis, many participants identified that they were too physically and emotionally depleted to pursue any form of formal complaint or negligence procedures. *"You tend just to shut down, and try to ignore that it's happening, because it's all too much to figure out."*

If participants did make formal complaints, they were more likely to be made by family members, such as mothers or partners. Further, when they did so in the past via the PALS system or switchboard structures, they found that no effort was made to correct the mistakes, or even an admission of negligence.

"I don't feel that the complaints are taken seriously, the Patient Advice and Liaison Service (PALS) will just write you a generic letter. I don't have faith in the NHS that they will ever accept accountability for any mistakes that have happened. They will always stick together because they don't want a costly lawsuit."

Other barriers included the fear of retaliation from certain medical staff, if the participant utilised their department frequently during acute pain crises and anticipatory stress. Iatrogenic harm is not only caused by the healthcare system, but it is also sustained by the existing structures meant to keep healthcare professionals accountable. Thus, the burden of accountability is implicitly placed onto patients struggling with chronic illness.

Participants' narratives highlight how institutional pressures, inadequate care pathways, and fragmented medical systems converge to produce and sustain preventable harm. This, in effect, shapes many sickle cell patients' responses within the healthcare system.

4. COPING MECHANISMS AND RECOMMENDATIONS

Participants expressed clear recommendations regarding the current treatment of sickle cell patients and ways to reduce medical negligence. Additional recommendations that have not been explicitly addressed in this article have also been included to acknowledge their importance in improving the care of SCD patients.

1. Implementation of routine psychological and neurocognitive assessments in a comprehensive Sickle Cell clinic.
2. Improvement of communication and documentation handling across multi-disciplinary teams.
3. General practitioners to be reviewed on their practice delivery for sickle cell patients.
4. Prioritising patient-centred care during procedures such as Intravenous cannulations.
5. Continued improvements to Sickle Cell specific training and education for staff and healthcare professionals.
6. Anti-racist education on opioid dependency and racial bias training towards pain.
7. Systems and structures of accountability for iatrogenic harm and adverse events should become more accessible for patients.
8. Further funding from NHS trusts to be allocated to sickle cell support groups.
9. Improvement in the procedures for escalation and medical treatment for organ damage, so that medical professionals address patient concerns within the shortest possible time.
10. Healthcare professionals should adopt a proactive approach to care planning for patients with Sickle Cell disease.
11. Developing flexible mental health models of depression, anxiety and grief presentation in black sickle cell patients.

A close-up portrait of a young Black woman with long, dark, wavy hair. She is smiling slightly and looking towards the camera. The background is plain white.

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