Your Pain and Mine: The mismatch between pain expression and perception of Sickle Cell Disease patients in the UK.

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Background: Transforming the scope of global health to become more equitable, especially in conditions such as Sickle Cell Disease (SCD), has been the subject of increasing attention. It has garnered significant focus within the National Health Service (NHS) due to rising patient concerns about pain undertreatment, institutional racism, and the need for culturally competent care. As much of SCD research originates from the United States, a gap exists in understanding the factors influencing pain expression and perception in SCD care in the NHS, especially from the perspectives of clinicians and medical trainees in the UK.

Methods: This study employed virtual semi-structured interviews with clinicians and medical students, through purposive and convenience sampling, to assess individual, social and cultural factors affecting pain perception and assessment in SCD care. The data was analysed using an abductive approach, combining inductive and reflexive thematic analysis with deductive refinement to align emerging themes with the research question. Considerations were made for the ethical framework of this study, including confidentiality and counselling available to participants, as well as for my positionality as a researcher with SCD.

Results & Discussion: Four main themes emerged in exploring factors affecting pain perception in acute care, including 1) knowledge gaps, 2) cultural attitudes toward pain tolerance, and 3) biases misidentifying SCD patients as “drug seekers”. The fourth and final theme, patient voices in education, proposed as a solution to addressing all of the above, underscores the importance of integrating SCD patient experiences into medical training to develop culturally competent care practices for improved pain management.

Conclusions: As someone with lived experience of SCD who has held roles as a researcher and an advocate, this study has made me more driven to put patient voices

within published literature because service provision, in any setting, which is not informed by patient experiences, will continue to miss the needs of the users.

Abbreviations

SCD- Sickle Cell Disease

VOC- Vaso-occlusive Crisis

NHS- National Health Service

ED- Emergency Department

HCP- Healthcare Professional

UK- United Kingdom

US- United States

NICE- National Institute of Care Excellence

NHLBI- National Heart, Lung and Blood Institute

NEWS- National Early Warning Score

VAS- Visual Analogue Scale

RCEM- Royal College of Emergency Medicine

PRISMA- Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Introduction: The Pain Gap.

Pain often transcends our ability to express it, creating a gap between those experiencing and those witnessing it. As described in *The Body in Pain,* by Elaine Scarry ‘‘…pain enters into our midst as at once something that cannot be denied and something that cannot be confirmed… to have pain is to have certainty; to hear about pain is to have doubt.” (Scarry, 1987, p.13). For individuals with Sickle Cell Disease (SCD), which is frequently accompanied by severe pain episodes, these breakdowns in communication can be especially poignant when seeking care within the National Health Service (NHS) in the UK (Sickle Cell & Thalassaemia All Party Parliamentary Group *SCTAPPG*, 2021).

SCD encompasses a group of inherited blood disorders characterised by an atypical haemoglobin (S) structure, which distorts the shape of red blood cells and reduces their oxygen-carrying capacity (CDC 2024). This often manifests as Vaso-occlusive crises (VOC), when hypoxia leads to sickled cells slowing and obstructing the flow within blood vessels. Termed ‘Sickle Cell crises’, these extremely painful episodes are the most common reason for presenting to the Emergency Department (ED) for those with the disease, and according to National Institute for Health and Care Excellence (NICE) guidelines used throughout the NHS, are acute medical emergencies (NICE 2012). Nonetheless, the persistent narrative of SCD patients, including myself, who are mostly of African or Caribbean descent, feeling mismanaged in the ED raises critical questions about why our expression of pain often does not feel believed by healthcare providers. It prompts us to ask: How does race and/or culture play a role in the way pain is perceived in the ED? This study aims to address a significant research gap; namely, how individual factors, alongside broader cultural and social ones, shape perceptions of patients’ pain in the ED.

Pain can be defined as the subjective experience of harm, actual or potential. The separation of pain from solely a symptom of physiological malfunction was encoded within

the International Association for the Study of Pain. There, pain is defined as “an unpleasant sensory and emotional experience associated with, *or resembling that associated with*, actual or potential tissue damage’ (IASP 2020). They note that pain is learned through one’s life experience and thus, it can be inferred that it is also inseparable from cultural influence as “the interpretation of pain behaviours is heavily dependent on the social and cultural learnings and understandings of both the person in pain and the observer” (Whitburn et al. 2019). Although it is arguably difficult to explore such factors affecting pain perception in an NHS ED, not understanding their contribution to clinical care will inevitably continue to result in dissatisfactory patient-clinician interactions and poor patient outcomes.

Literature Review: The current state of care

SCD, now the fastest growing genetic disorder in the UK, predominantly affects those of African-Caribbean heritage as well as a minority from Hispanic, Southern Europe, Middle Eastern and Asian descent (Pizzo et al., 2015; USDHHS, 2020). Within Sub-Saharan Africa, SCD is a significant public health concern- being most severe in Nigeria, a country with over 2.7 million SCD cases and the highest estimated disease burden worldwide (IHME 2021; Galadanci et al. 2014). As migration and settlement into the UK increase, which, in the year ending June 2024, was up 11% to 128.4 million passenger arrivals, SCD is one of the non-communicable diseases crossing borders and, therefore, is of global concern (Home Office 2024). Though the prevalence of those with SCD presenting in the NHS through Emergency Departments is rising, patients are often met with clinicians who lack an understanding of their pain, often falsely perceiving it as drug-seeking behaviour (De and Thakur 2024).

When presenting to the ED, patients experiencing a VOC require rapid pain relief, often involving opioids, as other painkillers, such as Ibuprofen or Paracetamol, have typically been tried without success. However, administering effective treatment is fraught with barriers. Despite NICE guidelines recommending that pain relief is administered within 30 minutes of presenting to the ED during a Sickle Cell crisis, patients often wait hours for pain relief, face a lack of clinician awareness regarding SCD, as well as stigma associated with being perceived as 'drug seekers' (SCTAPPG 2021). The tragic death of Evan Smith, a 21-year-old man with SCD who called 999 from his hospital bed because he was denied oxygen and a timely blood transfusion during a crisis, highlighted these challenges (BBC 2021). The subsequent "No One's Listening" report, written after the 2021 parliamentary inquiry, revealed multiple systemic failings for SCD patients as well as suggestions that institutional and interpersonal racism in the NHS underpinned the negative attitudes and stigma, as the majority of SCD patients are from African or Caribbean descent (SCTAPPG, 2021).

Sadly, my literature review continued to highlight research revealing low patient satisfaction with sickle cell care, especially when in an ED for a VOC. The majority of the studies, especially those involving patient perspectives, were based in the US, limiting their applicability to the UK, but they are important nonetheless in highlighting important areas for research and improvement for SCD care within the NHS. To address the main topics which came up, the literature review will be split into the following sections: Patient perspectives on SCD management, Clinician perceptions of SCD care, Understanding the UK context and its unique challenges and finally, The role of biases in ED.

Patient perspectives of SCD management

When patients present to an ED in the excruciating pain of a VOC, Crego et al. (2021) found that they are often met with long wait times, hours without pain relief and gaps in clinicians' knowledge about SCD. The survey, which was given to SCD patients in a North Carolina hospital with a dedicated Sickle Cell centre, also indicated that 60% of participants avoided the ED due to negative past experiences. Similarly, Linton et al. (2020) found that 66% of patients delayed or avoided ED visits even when in a VOC, with nearly 50% of the participants believing that ED physicians did not care about them. This dissatisfaction is not just limited to care received within hospitals but also extends to experiences in General Practice (GP). Aljuburi et al. (2012) found that across 40 SCD patients in London, the majority, 54%, were not satisfied with the quality of care from their GP, with one patient commenting, "The GP does not know anything about SCD pain and crisis. I would rather manage … at home or [go] to A&E where immediate action will be taken rather than call the GP who will ask us to book an appointment and more or less does not understand how to manage the pain or how severe or serious the pain is". The sample size limits the generalisability of this study's findings, considering approximately 17,500 people are living with SCD in the UK (Sickle Cell Society, n.d.). However, this distrust likely contributes to patients being avoidant of seeking care until the pain associated with the VOC becomes

severe and difficult to manage, further exacerbating feelings of dissatisfaction if they are still met with clinicians who don't believe or question the severity of the condition. (Jonassaint, 2021).

UK Context and Challenges

"There are many examples of excellent guidelines about how to look after people with Sickle Cell Disorders around the country. However, these are of no use if no one looks at them" (SCTAPPG, 2021, p. 18). In the UK, the NICE (2012) guidelines clearly state that VOC should be treated as an acute medical emergency with analgesia provided within 30 minutes, but in practice, this standard is rarely met.. An audit to assess the performance of VOC management at Cambridge University Hospital (CUH) in 2021- 2022 showed their median time to analgesia was 60 min (Zhou et al. 2023). Furthermore, only 17% of patients received pain relief within 30 minutes, a significant decline from the previous year, when it was 71%. Although the audit refers to one hospital within the UK, limiting its application to other EDs, it reflects a broader trend of worsening care for SCD patients in such settings.

Due to the busy nature of the ED, clinicians may be prioritising patients who have shown clinical signs of deterioration as opposed to patients in pain without any effects on their vital signs. This reliance on patient observations more than pain assessment tools when assessing how 'genuine' a patient's pain is could be further hindering prompt care for SCD patients. Even when patient observations, aggregated and documented as National Early Warning Scores (NEWS) in the UK, are used to aid clinical understanding of patients' pain, these too fall short (Royal College of Physicians, 2017). SCD patients may not exhibit normal pain responses like tachycardia or hypertension due to compensatory mechanisms from years of chronic pain, and research shows that pulse oximetry can overestimate oxygen levels in those with darker skin tones, which can lead a clinician to be unaware when a patient is deteriorating (De and Thakur 2024; Al-Halawani et al. 2023). Other clinical signs

of a worsening VOC, including pallor or jaundice, may even be overlooked with patients of darker skin tones (Mukwende, Tamony, and Turner 2020).

Role of biases in the ED

Biases also play a role broadly within interactions involving patients in pain in the ED, and more specifically for those with SCD. Best practice guidelines, for the Royal College of Emergency Medicine (RCEM) in the UK, recognised its role in care by mentioning how staff "need to be mindful of the effect that a patient's ethnicity or different cultural background might have on their own decisions about the provision of rapid and appropriate analgesia" (RCEM, 2021, p. 5). Structural racism, a term which applies here, has been defined as a 'system of organisational and institutional policies created over time that support a continued unfair advantage for some people and unfair or harmful treatment of others based on their race or ethnic group' (NIH, n.d.). Anna Hood (2025, r848), writing on racism in pain management, argued that "this racism goes beyond individual prejudice; it is often built into the foundations of medical education and practice." It can be as overt as ethnic disparities in pain management (Cintron and Morrison 2006), clinicians believing Black Individuals have a higher pain tolerance than other races (H. A. Washington, 2009), or as subtle as underfunding of research for conditions affecting those of African or Caribbean descent.

Recent research by the NHS Race and Health Observatory (NHSRHO, 2025) as part of a comparative review of Sickle Cell Disease (SCD) highlights this starkly. Although Cystic Fibrosis (CF) and SCD are both genetic conditions affecting similar numbers of patients in the UK, CF—predominantly affecting those of European descent—receives two and a half times more research funding and has two specialist nurses per 100 patients, compared with just 0.5 per 100 for SCD. This imbalance persists despite SCD-related hospitalisations costing the NHS nearly twice as much annually as those for CF. However, evidence on the role of structural racism in emergency department (ED) pain management is mixed. For

instance, Ware et al. (2012) reported no significant differences in wait times or opioid administration by race or gender. Still, attributing disparities solely to ED practice risks overlooking the deeper issue: the underrepresentation of minoritised ethnic groups in chronic pain research (Boyd et al. 2024, no. 8). Without addressing these systemic gaps, efforts to mitigate interpersonal bias remain incomplete.

Conclusion

The literature highlights significant challenges in managing VOC in the ED, specifically in the interactions surrounding patients in pain, including adherence to national guidelines and clinician biases, plus the use of pain assessment tools. This study aims to address these themes by exploring clinicians' and medical students' perspectives on the factors underpinning pain perception and assessment in the ED, and more broadly across their interactions and experiences with SCD patients. Having an adequate understanding of Sickle Cell education in medical schools and how pain is perceived during placements plays a key role in establishing clinical understanding surrounding how to handle a SCD patient in pain. Then, discussing with clinicians who have treated SCD patients across a variety of roles within the hospital also paints a more holistic narrative around how individual factors, culture and race intersect to influence their perception of those in pain and seeking pain relief in the ED. Overall, this study aims to develop an understanding of pain in its broader elements, exploring factors influencing our ability to perceive it as it is experienced, as well as judging how pain can be better assessed for the improvement of SCD management in the ED.

Methodology: To Study Pain.

Study Participants

A qualitative study was conducted to understand the individual, social and cultural factors influencing pain assessment and pain management of SCD patients in ED through the use of purposive sampling from the experience of medical students and clinicians. Interviews were conducted with these two participant groups- medical students in their final or penultimate year and clinicians who had been part of the care of SCD patients before the study- as I felt both groups had particular knowledge and experiences relevant to my research question. Students, particularly because they may have a birds-eye view of communication within the hospital, witnessing several interactions between patients in pain and clinicians during placements. Additionally, students could provide an insight into how SCD is taught within medical schools across the UK, which will influence their confidence in managing such patients later on. Clinicians, defined within this study as a qualified healthcare professional who works directly with patients, as opposed to in research, were also an integral part of this study (Vocabulary.com, n.d.). Specifically, those who had been part of the care of SCD patients. This was to gain first-hand insight into the individual, social and cultural factors influencing the care of SCD patients in the ED through what they have witnessed. Convenience sampling was carried out for both groups of students and HCPs, and they were contacted via a range of personal and interprofessional networks or groups.

Data Collection

Before conducting the interviews, participants completed a survey detailing demographic data such as hospital trust and role, as well as school and year of medical training for students (Table 1).

Table 1- Participant Demographics

		Participant number	n
Students	4th-year medical students	P1, P8	2
	5th-year medical students	P2, P3, P6	3
Clinicians	Doctors	P5, P7, P9, P10, P11, P12, P14	7
	Multi-Disciplinary Team (Nurse, Physiotherapist, etc.)	P4, P13	2
		Total:	14

Between May and July 2024, semi-structured interviews were conducted, which enabled an in-depth exploration of pain perception and assessment from the perspective of the participant. A study poster was created, and students were recruited via personal networks and clinicians through email or messenger dispersal. Each interview occurred on Microsoft Teams, lasted between 45 and 60 minutes and was transcribed verbatim using the Record and Transcribe tool within Teams. Participants were sent the Study Information sheet, alongside the consent form and were notified of their right to withdraw their involvement at any time during the study. Signed copies of the consent forms were received before recording participants with the transcription software; verbal consent was also attained.

Interview questions were informed by current literature on SCD with a focus on gaining insight into the experience of interview participants, through what they have witnessed in placements or been taught as medical students, and what clinicians have experienced of SCD care in ED. Interviews were conducted until data saturation was reached at 14 study participants, when no new codes or themes were emerging from the data set. This also coincided with the final four weeks of the project timeline, allowing sufficient time for detailed analysis, interpretation and writing.

Data Analysis

I independently analysed the data using an abductive approach, combining inductive thematic analysis to identify themes emerging from the interviews with a deductive lens to refine and organise these themes in relation to the research question (Braun and Clarke, 2022; Byrne, 2022). Reflexivity was also maintained to ensure that the quotes selected within each theme accurately reflected the data as a whole. After each transcript was read through and put into codes using the online software Taguette, all data was re-assessed, inspected and edited with the recorded interview. Finally, these transcripts were downloaded and organised within NVivo for the extraction of relevant sub-codes to group the data into themes that linked several data sets together. In effect, four themes were established from the interviews: ‘knowledge and experience of SCD’, ‘attitudes to pain tolerance’, ‘differentiating patients from addicts', and finally, ‘patient voices in education’ as participants discussed solutions for bridging the gap between pain expression and perception.

Ethics

Ethical approval for this study was obtained from the Ethics Committee in St George’s University, London (REC reference 2024.0111). Confidentiality was upheld by instructing

participants not to disclose any patient-identifiable information when recounting clinical cases and anonymising their identities using participant numbers during the write-up. To address the most likely risk, participants were advised to contact St George's Counselling Team via the email provided in the Participant Information Sheet if they experienced any distress relating to what was discussed during the interview.

Reflexivity & Positionality

As someone living with Sickle Cell Disease (SCD), this research holds deep personal significance. Whilst I did not interview individuals living with SCD and may not be classified as an “insider” in the conventional methodological sense, I bring an insider perspective to the subject matter through my lived experience of vaso-occlusive crises and pain management within UK emergency departments (Dwyer & Buckle, 2009). It was these personal encounters that initially sparked my interest in exploring this topic in greater depth.

One particular incident, often recounted by my parents, has stayed with me over the years. At around seven years old, I experienced a severe crisis in both my legs and was taken to our nearest emergency department. Despite my parents’ best efforts to advocate for timely assessment and adequate pain relief, they were met with limited progress in the hours that followed our arrival. Their anxiety and frustration grew—until a Nigerian doctor began his shift. Upon reviewing my condition, he swiftly initiated a blood transfusion. My parents recall him later telling them, once I had shown clear clinical improvement, that had the transfusion been delayed much longer, my chances of survival would have significantly diminished.

This formative experience—and hearing others like it from my network—profoundly shaped my motivation for this research. It reinforced for me the vital importance of timely, empathetic, and informed clinical responses in the emergency care of SCD patients and

prompted me to investigate how culture and race influence these interactions. I hope that this study contributes meaningfully to improving understanding, communication, and equity in acute care for SCD patients. To this end, I am aware that my lived experience as a patient could add a certain subjectivity to my research and reflecting on this before and throughout conducting my research was essential (Olmos-Vega et al. 2023, 241–51). For example, it is possible there could have been a skew towards assessing factors underlying instances where pain assessment and management did not go particularly well, as opposed to when they did. To mitigate this, I made sure the interviews involved open questions, as well as making a conscious effort to explore any instances mentioned that exhibited prompt and effective responses to SCD patients in pain.

In addition, participants who did not know me before being involved in the study were not informed that I had SCD, so there would not be any changes to their responses when being asked sensitive questions about their experiences. Nonetheless, it could have affected the responses from those who knew that I have the condition I am researching- possibly to inhibit true feelings on the subject, or equally, on a positive note, to enhance responses by participants giving more thoughtful answers because they are aware it is being conducted by someone with an insider perspective. Being a SCD patient, medical student, and researcher was an intersectionality which offered a privileged insight into the topic at hand as much as it made it difficult to remove the biases involved. Nonetheless, an effort was made not to discuss my personal experiences with participants throughout the research project.

Results: Nothing about us, without us.

In response to the research question of finding individual, social and cultural factors influencing pain perception and assessment, themes which covered these three areas were chosen. For individual factors, ‘knowledge and experience of SCD’ emerged, and when addressing cultural factors, ‘attitudes to pain tolerance’ was the main theme. Social factors highlighted ‘differentiating patients from addicts', and when asked to reflect on solutions to bridge the gap between pain expression and perception in ED, ‘patient voices in education’ was the final theme that arose. The interactions between these themes and the research question can be pictured in Figure 1.

Factors concerning individuals

Knowledge and experience of SCD

This theme highlights participants' assertion that healthcare professionals who are knowledgeable and have experience with SCD patients are more likely to believe those experiencing a VOC in the ED and thus, better manage their pain. However, even in medical schools, SCD education varies between curricula, and there was an emphasis on students feeling that SCD has been largely self-taught.

I don't think I've had a lecture on sickle cell… and I think not a lot of people, unless you're a medical student, understand how much of the course is actually self-directed.
P2

I think most of what I learned was through question banks like PassMed and like my own research on like little bits here and there. So I think that the uni could definitely do more in terms of sickle cell teachings.

P6

Although it was pointed out that this self-directed approach to learning was not just exclusive to SCD, some students may place more emphasis on learning conditions which are included in teaching sessions more often. Even when Sickle Cell makes it into teaching sessions, there are alternating views on how successful this may be. One student mentioned that even though the lecturer stated the pathology of the condition, they did not quite articulate the signs of a VOC in a patient, which left her feeling like the teaching session was not effective.

The consultant spoke a lot about how it's really important to recognise sickle cell in patients. And that was kind of where it stopped. So, she kept hammering the importance, but never really like taught people what are the features you're looking for, though?

P1

However, other participants felt that SCD was taught adequately over different years within the curriculum, which highlights that these individual disparities are also tightly related to how medical institutions prioritise Sickle Cell teaching.

I think the teaching has been good, and by good, I think that it has been covered as much as other important conditions... I've just done my haematology week.. so they've covered it again in quite a lot of detail, actually. I*n terms of experience, I've not met a sickle cell patient on the wards. I think it's greatly to do with the demographic.*

P8

When mentioning ‘demographic’, the participant was referring to not seeing many people of African or Caribbean descent within her placement hospital, which SCD patients in the UK fall mostly within. This affects the confidence that students and, eventually, healthcare professionals have in assessing and treating patients with conditions they have only encountered within presentations and lectures. Even though it is not an excuse to not be aware of SCD, one clinician implies that the infrequency of such patients in a particular hospital factored into the staff's misunderstanding of SCD pain and its complications.

Conversely, clinicians who frequently encounter Afro-Caribbean populations within their hospitals may still not be confident managing SCD patients because of the opiate medications being requested, or needed, in a VOC. One participant pointed out that this hesitation on the part of the clinician may be falsely translated by the patient as their pain not being believed.

I think it's more just like you're like, I actually, I'm not sure what to do here, but that comes across, I think, sometimes as like not believing someone. And I think sometimes it's maybe hard to articulate, I do believe you. I really don't want you to be in pain. I'm just less sure about the tools to use to achieve that.
P7

I guess as I became more exposed, more familiar to handling these big opioid drugs for the sickle patients, I can safely say, look, I can manage this pain adequately. And even if it does have its side effects, I can manage that too. You become a bit more experienced in how to handle these things.
P5

As outlined in this section, multiple factors shape whether clinicians feel prepared to manage a patient in a SCD crisis. For medical students, this ranges from the quality and quantity of teaching to self-directed learning and the demographics of patients encountered during placements. Among HCPs, perceptions of pain were often linked to the number of SCD cases they had managed, particularly their experience prescribing high-dose opiates, where hesitation could be misinterpreted. However, knowledge and clinical exposure alone do not account for the cultural factors that influence pain perception and management.

Cultural Factors

Attitudes to Pain Tolerance

When participants were asked how culture plays a role in pain expression and perception, a common acknowledgement was that it is through the role of pain tolerance, both of the one experiencing their pain and of the one assessing pain. This does not mean to imply that an individual can tolerate varying levels of pain simply because of their culture, but that their perspective of pain tolerance is influenced by their cultural attitudes and beliefs about pain expression. This, as participants describe, can affect interactions clinicians have with patients in pain.

Two participants mentioned that coming from Nigeria, where the cultural norm in certain areas is limited expressions of pain, this influenced their interpretation of others experiencing pain. In one sense, it may make one think that a patient being vocal about their pain means they are just not 'resilient' enough.

I think for someone like me, the fact that you know, I grew up in Nigeria, I feel like people grew up in that sort of much more resilient culture, so, um.. So, if I saw someone in pain, you know, thrashing about, crying, potentially I could say, you know, what's going on, they

shouldn't be doing this, but obviously recognising that bias that potentially they could actually be in significant pain.
P14

OK, let me use Nigeria as an example now… most of the patients I treated in Nigeria, you will not see them really crying. They'll be moaning, moaning, trying to hold it, grinding their teeth, shaking their leg or holding on to something and shaking that thing before you see them really screaming, then you will know that it's really gotten out of hand.
P4

As most SCD patients are of African or Caribbean descent, learning about such cultural interpretations can be pivotal to understanding patient behaviours in the ED. For example, another participant explains how the cultural perception of clinicians may also influence pain expression.

As I said, most of the sickle cell patients I've met are of African origin, when it comes to respect, because we're trying to be respectful, sometimes we're not able to, like, express ourselves confidently. And that is a cultural thing. Because here it's easy for a patient to just tell you. Hey, Doctor, I'm actually in pain and I don't think I'm being cared for properly… But the cultural part of it is that you can see the African person might be a bit wary of saying that because of their respect, you know, for doctors and authorities back home in Nigeria.
P9

For patients like these who are coming from such cultural settings to the UK, where the NHS places a great emphasis on patient autonomy, it can be difficult to be an advocate for oneself, especially when in pain. As explored, these factors can easily influence whether a patient in pain feels ignored or acknowledged, and, similarly, culture can affect how clinicians interpret their patients' pain behaviours. Understanding these influences in pain

management is important, nonetheless, in providing care that is holistic and patient-centred. Although the next theme comes under social factors because it involves elements of race and bias, it is also very closely linked to this theme, because it involves an element of exploring the culture of the ED, where staff often feel they must 'discern' how genuine one's pain is.

Social Factors

Differentiating patients from addicts

As race is inextricably linked to societal definitions and norms, the subject of conscious and unconscious biases which play out in pain communications falls under the umbrella of societal factors. Here, participants commonly referred to the dilemma of staff members scrutinising patients claiming to be in pain because of the possible risk of furthering opioid addictions in the ED. Participants often encountered patients who were negatively affected by these biases, and one clinician described a disturbing case he witnessed of a family member in a VOC being mistreated as a result.

I remember one of those experiences, a male nurse just came in and just took out her cannula and was like, no, you're not receiving any pain medication anymore. I feel because she was requesting for more medications, they kept feeling that she was just drug seeking or medication seeking. But the truth is that this person doesn't really understand what a sickle crisis is. I think it's a knowledge thing, and that knowledge thing causes the person to be biased.

P9

Furthermore, the concept of looking for 'physical evidence' of one's pain is a common thread during this theme, with the investigation workup which commences when a patient presents to the ED. Not finding any obvious abnormalities can lead to clinicians feeling suspicious of one's motive for presenting.

So, when we see patients that are recurrently presenting to the A&E you know with pain, I think sometimes we do label them that you know they are drug seeking. I mean, there have been potential missed cases, you know, missed diagnosis, simply because of that bias of that judgment or prejudice about someone frequently seeking care when maybe previously nothing really has been found.
P14

One participant mentioned in particular that these encounters with those who demand opioids and do not seem to reflect the pain they claim when being further assessed can result in clinicians being more suspicious.

OK, somebody saying I have pain in my joints but when you're moving the joint, they are not experiencing pain, they are relaxed. And then oftentimes they are very demanding, those few patients that may be seeking opioid use because they don't have money to buy in the community. There are very few. But I'm saying that this factor actually has caused many doctors to be more observant in terms of assessing patients to have sickle cell.
P11

Nonetheless, being 'demanding' is a concept which fluctuates in its interpretation. Another participant commented that SCD patients may be wrongly classified as such when they are simply advocating for themselves.

I find that a lot of the sickle cell patients I've seen in hospital they just kind of like suffer in silence. And then when you get the very few that actually don't accept suffering in silence and do make a big deal about the fact they need pain medication or they have somebody with them that is advocating and almost like angrily letting the nurses know that this person requires this pain medication, I think I see a lot of tutting, a lot of believing that people are just like drug seeking behaviours and things like that.
P1

Biases do not just remain with one individual but often have a lasting effect on the social structure where they occur. After being part of the care of a SCD patient who was in such a great level of pain that they could not be further assessed without starting on an oral opioid, one clinician recounted:

I was looking at her previous entry and someone had written, oh, this patient is what's it called opioid seeking behaviour and I'm reading it, and I was thinking this patient's in excruciating pain and this person's written this patient's got opioid seeking behaviour when they haven't considered the multitude of other issues this patient had going on
P10

If looked at by other staff who had not encountered the patient, but had no reason to disregard the comment, this would have a ripple effect, furthering a stereotype which affects their management by others. However, clinicians and students frequently emphasised that such biases are heavily influenced by structural pressures, such as patient volume, staff and bed shortages, which increase the likelihood of patients' pain not being adequately addressed.

I think, currently right now it's just the shortage of staff. I think the NHS is in a massive crisis where clinicians are under pressure to see patients within a certain time and get them discharged.
P1

Workload pressure is so much that for people who have already stereotyped some people, they will see them as the least of their problems... they will rather want to go to patients that they think are dying to them.
P4

There are so many patients and bed blocks as well... I think just the cognitive overload is so much that you just, your fuse is short.. you're not able to really spend as much time as you n\d like with each individual patient.
P12

I suppose if it's a less busy day, I suppose you're more likely to do more exploration. Be a bit more, sort of, you know, attentive and probably just do things a bit better. Because again, apart from just medications, you know, listening to people, giving them that attention is also a form of, you know, psychoanalgesia you could call it.
P14

This theme highlights the biases which occur when patients frequently present to the ED, express their need for pain relief and have pain management strategies that are misinterpreted by HCPs. Nonetheless, it would not be fair to dismiss the institutional pressures in the NHS, which increase their likelihood of recurrence.

Solutions

Patient voices in education

When discussing solutions, alongside institutional and interpersonal changes, came the subject of patient voices. Understanding the lived experiences of patients is more effective for correcting misinterpretations of pain than the addition of protocols.

I think education, awareness... I can tell somebody who has experience with sickle versus one who does it, and the experience those patients go through is vastly different. I think the problem with protocols is you'll tend to find that people will tick the box and then once that box is ticked, that's done and there's no protocol robust enough to give patients what they need.

P5

…groups of patients that you can relate to, and you can see wow, like this is a whole person, this patient lives with this day-to-day. This is how they cope; I feel like that instils empathy in someone.

P7

As opposed to relying on textbook details to describe the clinical features which may or may not be apparent when a patient is in a VOC, participants noted the benefit of involving patients for a realistic understanding of the challenges during a VOC and what they can do to alleviate them.

Let them tell you this is what we experience, this is what people that are in my demographic say that their hospital experience is like, and this is how you can change it.

P1

A participant who had implemented this through an interactive teaching session for junior doctors reported how impactful it was. The session involved a video of a mother recounting how her son with SCD died due to several inadequacies within his management.

I think here, where we introduce the emotional aspect to it, a lot of people went away saying, wow, that was quite... that was quite deep, and I think that's empathy. Well, the next time you have a sickle cell patient in front of you, you'll see the live patient you had in simulation and the mother talk about the real case of her son. I think that drives home empathy, where it's not typically there.

P5

Overall, this theme highlighted how crucial it is for SCD education, within medical school and on the wards, to be shaped around patient voices and experiences, which leave a lasting impression on those who are taught, so even in high-pressure situations, they may be more inclined to remember the way patients reported to have felt. As the saying goes, 'nothing about us, without us'.

Discussion: The Standard of Care

To explore the individual, social, and cultural factors shaping the expression and perception of SCD pain in UK EDs, this study identified three major themes in response to the research question: Knowledge and experience of SCD, Cultural attitudes to pain tolerance, and Differentiating patients from addicts. A fourth theme, Patient voices within education, arose from participants' suggested solutions for bridging the gap between pain expression and clinical interpretation.

Although interconnected, the factors influencing pain management varied between individuals, particularly regarding knowledge and clinical experience of SCD. While SCD is included in the Medical Licensing Assessment (MLA) content map, the depth of student understanding often depends on self-directed learning and exposure during placements (GMC, 2023). Consequently, knowledge gaps begin in medical education and are compounded by limited clinical experience, especially in NHS regions where SCD is rare (Baker, 2023; ONS, 2022). One participant described a case where a patient was denied analgesia because clinicians doubted the severity of VOC pain, despite NICE guidelines describing it as life-threatening. Such incidents illustrate how limited awareness of the lived experience of SCD fuels implicit and explicit biases, perpetuating testimonial injustice—a form of epistemic injustice in which prejudices about race, gender, or identity undermine the credibility of the speaker (Fricker, 2007). As Gopal et al. (2021) argue, awareness of bias requires clinicians to ask: *If this patient were different in race, age, sex, or gender, would I treat them the same*? To extend this further, I propose an additional question: *If the cause of this person's pain were different, would I treat them the same*?

As one participant highlighted, it is also possible that delays in pain management are misinterpreted as maltreatment when it is a clinician's hesitation to manage SCD patients due to complexities with and inexperience with the medication involved, especially opioids. During these scenarios, it is assumed that their care plan, a document providing tailored care instructions co-produced by the patient, their primary care physician and their specialist multidisciplinary team to aid any clinician with details of the medication and support needed in a VOC, should bridge this gap. However, even though availabilities of these plans are increasing due to digitalisation, research from the NHS Race and Health Observatory commissioned consultancy, Public Digital, found a lack of individual care plans in place as well as no definition of what one should constitutes of and even when they do exist, most were paper based and often dismissed by HCPs (NHS RHO, Public Digital 2023, 41–42).

Awareness is only one dimension influencing acute pain management; cultural background also shapes interpretations of pain behaviours and attitudes toward tolerance. Although this study cannot fully capture culture's complexity, historical contexts remain relevant. In the United States, racial disparities in pain care can be traced to colonial practices and racist ideologies, including the false belief that Black people had less sensitive nerve endings and could therefore tolerate more pain (Hoffman et al. 2016 4296–4301; Smedley, Stith, and Nelson 2002). Similarly, cultural perspectives are often passed down across generations and continue to influence present-day attitudes, even if they do not reflect the experiences of all. For example, two HCPs of African descent who had worked in both Nigeria and the UK described how norms in Nigeria—such as deference to clinicians as authority figures or only expressing pain when it becomes unbearable—can shape patient behaviour. Such patients, when treated in the UK, may feel less able to advocate for themselves during delays in care. This example illustrates the need to consider how such beliefs, whether held by clinicians or patients, can significantly shape encounters in acute care.

Beyond cultural interpretations, clinicians identified another key challenge: the misidentification of SCD patients as ‘drug seekers’ rather than individuals in acute pain. UK guidelines, from the Royal College of Emergency Physicians, RCEM (2021, p. 6), acknowledge the difficulty in assessing whether pain is genuine but emphasise that appropriate analgesia should not be withheld. However, there is limited clarity on what constitutes a ‘drug seeker’ or ‘opioid addict’ (RCEM 2017), leaving care dependent on individual clinician perceptions. As highlighted in previous themes, these perceptions are shaped by knowledge gaps, experience with SCD, and cultural interpretations, meaning that patients advocating for prompt pain relief may be wrongfully labelled as ‘demanding’ and dismissed. Studies confirm this bias is common, yet it is rarely addressed in educational materials (Masese et al. 2019; Linton et al. 2020).

Furthermore, systemic pressures in the NHS—high patient demand, limited beds, and time constraints—further compound these biases by increasing the likelihood of rushed interactions (The Medic Portal, 2024). Institutional solutions are therefore essential, including referral tools to escalate concerns, increased staffing, and well-being support to mitigate desensitisation to patient pain. A teaching resource for ED nurses emphasises, ‘the clinician must take a leap of faith, look beyond clinical biases, and allow the patient to drive his or her own management of the disease. No one knows their level of pain or what works for them better than the patients themselves. This is the standard of care.’ (Reddin, Cerrentano and Tanabe, 2011).

Incorporating the lived experiences of SCD patients into education can address knowledge gaps and stereotypes while highlighting cultural norms that shape pain expression. Employers, such as the NHS, have a duty to train clinicians to recognise and mitigate epistemic injustices, defined by Ian Medina and Gaile Pohlhaus (2017) as a “close-mindedness to the possibility that others may experience the world in ways they cannot”. Clinician advocacy is particularly important, as during VOCs, patients who perceive their

pain is dismissed are less likely to speak up for themselves. Compassionate care requires clinicians to step into the patient's world, listen attentively, validate their pain, and act swiftly in their best interest. Although systemic pressures can impact the quality of such care, employers must reinforce its importance through cultural awareness, targeted communication skills training, and patient-centred approaches to pain management. When these are specifically designed for clinicians caring for SCD patients, they become a valuable adjunct in addressing biases and barriers in emergency care settings (Thomas and Cohn, 2006). Auditing these interventions can be done pragmatically through time-to-analgesia and time-to-specialist input when this is needed, to ensure institutional strategies translate into improved patient experience.

Limitations

Whilst this study highlights issues within SCD education, biases in care, and the need for employer-led initiatives to improve culturally competent practice, its findings are not intended to be statistically generalisable. Instead, qualitative research aims for transferability to similar contexts, and the sample of 14 participants was sufficient, as data collection continued until saturation. Nonetheless, certain limitations remain. For example, only four medical students were interviewed, and although they attended different schools, it would be premature to conclude that SCD is absent from all medical curricula. Similarly, while the 10 HCPs interviewed represented various NHS Trusts, not all had direct experience with SCD patients in the ED, meaning conclusions about implicit or explicit bias cannot be assumed to apply across all Trusts or emergency settings.

While this study strongly advocates for the inclusion of patient and public involvement (PPI) in research, it was not possible to interview SCD patients within this study due to time constraints. This is acknowledged as a limitation, as the insights gathered could be further enriched by those with lived experiences of SCD in the UK and their experiences within an

NHS ED. Nonetheless, I believe that through my insights as someone living with SCD and my personal network of support and advocacy groups, my research incorporated patient insights through a variety of different means, and I was encouraged by the importance of studies like this. Future research should aim to integrate patient perspectives from the outset, both to validate and expand upon the findings presented here, and to ensure that care recommendations are meaningfully informed by those most affected.

There were also limitations with the choice of thematic analysis to contextualise results from this study. As highlighted by Bazeley (2013), by relying on codes and themes as a form of analysis, the perspectives of cases highlighted by participants can be lost. In this study, they were asked if they had witnessed a case where a clinician did not believe someone's pain, and it may have been useful to describe such cases rather than draw generalisations or take snippets to build established themes. Using alternative approaches such as interpretative phenomenology, narrative, or discourse analysis could have offered a more in-depth understanding of the experiences of each participant to better answer the research question.

Nonetheless, even though there could be improvements to the design and execution of this study, HCPs from different NHS Trusts and medical students from different institutions across the UK, providing examples and experiences which complement each other, show how essential research on SCD is nationwide. Further studies can build upon this work by interviewing clinicians within every NHS trust across the UK to truly have a snapshot of SCD care in ED. It would also be helpful to mirror this for students, interviewing a portion of them in all medical schools who are in their final year to understand if, and how, SCD is taught.

Recommendations

From this study, the following list of practical suggestions, split between institutional and interpersonal, can be implemented to elevate the standard of care for SCD patients (Table 2).

Table 2.

Institutional
This project recommends a nationwide study to discover how SCD is integrated within the curriculum of every medical school in the UK, with the aim of including resources that are reflective of the patient experience (e.g. videos SCD patients have made and shared online).
NHS Trusts to mandate all clinicians to undergo SCD teaching co-created with patients and communication skills courses to develop cultural competency in the ED.
NHS Trusts to use eligible funding obtained from UK Research and Innovation (UKRI) to support audits, tracking and shortening the 'time to analgesia' when a SCD patient presents to their ED.
NHS England, RCEM and relevant bodies to define what constitutes an ‘opioid addict’ in guidelines for acute pain management and provide a structured referral pathway for HCPs to escalate concerns. Guidelines should also acknowledge how stigma and labels affect the care of SCD patients.
Interpersonal
All HCPs are to confront bias and negative attitudes when interacting with a SCD patient by asking themselves, 'If the cause of this person's pain were different, would I treat them the same?'

Conclusion: It starts with us.

In conclusion, this study highlights the urgent need to improve SCD care across NHS EDs. Through a detailed exploration of individual, social, and cultural factors influencing the expression and perception of SCD pain with medical students and experienced clinicians, several critical themes emerged which aligned with findings from the literature review. These include the varying levels of knowledge and experience of SCD, inconsistent interpretations of pain through the lens of culture, and the troubling need to differentiate between patients in 'genuine pain' and 'opioid addicts'. To address the knowledge and experience gap, this study advocates for integrating patient voices into educational materials, emphasising the role of patients as experts. Furthermore, this study advocates for research into defining opioid addictions in the ED as well as increasing NHS funding to combat pressures compounding the likelihood of biases towards SCD patients.

Although the study's scope is limited by its small sample size and method of analysis, the consistency of findings across a multitude of NHS Trusts and medical institutions, which aligned with US-based findings within the literature review, underscores the nationwide relevance of these issues. These insights are relevant worldwide and provide scope for future research to develop a more comprehensive understanding of SCD care in medical institutions around the world. We will undoubtedly continue to see a rise in globalisation and a need for empathetic, informed and equitable care, no matter where a patient is accessing it from. By implementing these changes in medical education and clinical practice, there is hope to improve the quality of life for those living with SCD significantly, ensuring their pain is recognised, understood, and appropriately managed.

Written articulately by the National Advisory Group on the Safety of Patients in England (NAGSPE), HCPs must ‘hear the patient voice, at every level, even when that voice is a

whisper'. (NAGSPE, 2013 p. 17). As a researcher with SCD, this study has made me more driven to put patient voices, especially those like mine, within published literature because service provision, in any setting, which is not informed by patient experiences, will continue to miss the needs of the users. I envision a future of SCD research where patients are within research teams, advocating for their voices to be heard in literature and clinical practice, for generations to come. Ultimately, it starts with us.

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