

BMJ Open Black sickle cell patients' lives matter: healthcare, long-term shielding and psychological distress during a racialised pandemic in England – a mixed-methods study

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ABSTRACT

Objective To understand the psychological and social impact of shielding on people with sickle cell disorders and their carers in the Midlands region of England. This region was badly affected during the pandemic, with the city of Birmingham having some of the highest rates of COVID-19 deaths.

Design A mixed-methods project with a quantitative survey on shielding and adapted SF36 V.2 questionnaire, which was supplemented by qualitative semistructured interviews analysed using interpretive phenomenological analysis (IPA).

Participants Fifty-one participants who were predominantly of Black Caribbean or Black African heritage anonymously took part in the online survey. We supplemented this with eight in-depth semistructured interviews with adults with sickle cell disorders using IPA.

Results The adapted 36-Item Short Form Survey (SF36) version 2 (V.2) survey indicated worse quality of life and mental health. The open-ended questions from the adapted survey also identified shielding concerns about hospital care, pain management and knowledge of sickle cell by healthcare professionals. From the interviews, it emerged that the racialised element of the pandemic caused significant psychological distress for a population group that had to regularly access hospitals. It was noted that psychological health needs both during a pandemic and outside of it were poorly understood and became invisible in services. The psychological impact of experiences of hospital care as well as growing up with an invisible chronic condition were important to understand psychologically.

INTRODUCTION

This study sought to investigate the psychological and social impacts on people from an ethnic minority with a genetic condition who had been asked to engage in long-term shielding during the pandemic. Sickle cell disorders (SCDs) are one of the main inherited genetic conditions in the United Kingdom (UK) and mainly affect people

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This sequential mixed-methods study, based in Midlands region in UK, found that patients from an ethnic minority background who are asked to shield during a racialised pandemic will experience psychological distress.
- ⇒ Findings from COVID-19 data are from an area with very high COVID-19 deaths not generally given attention, but the small sample size is a limitation.
- ⇒ As found in the literature, mixed-methods analysis indicated that shielding concerns for Black people with sickle cell were about lack of preparedness of hospitals, bad care affecting pain management and general lack of understanding of their condition.
- ⇒ Interpretive phenomenological analysis (IPA) revealed that fears of going into hospital during the pandemic were also linked to present and past experiences with unethical care and racism.
- ⇒ Despite the impact on Black patients, there was an invisibility in services of intergenerational psychological distress and trauma on families.

of Black and ethnically minoritised (BEM) origins.¹ Approximately 15 000 people are estimated to be living with SCD in the UK, but these figures are likely to be underestimated.² The figures also exclude families and caregivers who are impacted too. Early on, during the COVID-19 pandemic, people with SCD were identified as 'clinically extremely vulnerable' (CEV) and asked to 'shield' (stay at home) by the government in March 2020. This was initially for a 12-week period, which was subsequently extended and lasted a year until shielding was 'paused' on 1 April 2021 and ended in September 2021 with the closure of the Shielded Patient List. The success of the vaccination campaign, and development of new treatments, meant the end of shielding and need to identify people



as CEV. However, people with SCD are still identified as having compromised immune systems and thus at higher risk of getting seriously ill from COVID-19, despite vaccinations.

SCDs are inherited complex multisystem conditions that manifest differently in each individual person but are typified by experiences of haemoglobin-forming sickle cell shapes that can lead to vascular occlusion and severe pain called 'crises'.³ Other common complications include fatigue caused by anaemia, organ damage, stroke, chest infections, difficulty breathing and fever. An SCD crisis can be serious, need urgent hospitalisation and can be life threatening. Triggers for symptoms can include environmental factors such as lack of nutrition or hydration, infections, too much exercise, extreme temperatures or windy weather⁴ and also stressful situations, all of which can be influenced by socioeconomic conditions too.⁵ There are also differing variants of SCD influencing severity of the disorders, with HbSS generally viewed as more serious and HbSC as milder.³ Regardless of variant, some people with SCD may also need to go to hospital on a regular basis for monthly blood transfusions or when they have a serious pain crisis. Yet, the way that SCD manifests is unique to each person. In some people, it can be a manageable chronic condition and invisible to outsiders; in others, it is a disability, and for some, it can be acute, and in one and the same person, it can be all of these things.¹

While shielding was 'paused', restrictions for CEV people, like those with SCD, continued as new variants of the SARS-CoV-2 virus spread, and they were asked to get vaccinated as well as continue taking precautions. According to Office of National Statistics data,⁶ some CEV people continued to shield, primarily in areas where there was greater risk. The Midlands region with cities of Birmingham, Nottingham, Derby, Coventry and Leicester was one of those areas and was particularly badly affected by COVID-19. The highest number of COVID-19 deaths during the pandemic was recorded at University Hospitals Birmingham NHS Trust, the fourth highest at University Hospitals of Derby and Burton NHS Foundation Trust and eighth highest at University Hospitals of Leicester NHS Trust.⁷ It has also had the highest levels of restrictions during England's three periods of lockdown, with cities like Leicester and Birmingham, as well as entire boroughs like Sandwell, also experiencing the second highest tier 3 restrictions during non-lockdown periods.

In these regions, like elsewhere during the pandemic, BEM people were disproportionately impacted by COVID-19,^{8,9} with excess deaths in the West Midlands¹⁰ and mental health negatively affected overall.^{11,12} There has been a higher rate of mortality as well as morbidity among BEM people giving credence to perceptions of stratified risks with indications of inequalities in access to healthcare.¹³ It is known that shielding increased experiences like loneliness and social isolation¹⁴ as well as depression and anxiety,¹⁵ disproportionately affecting populations in lower socioeconomic groups, women,

single people, parents and those with pre-existing mental health conditions.¹⁶

The galvanising of the Black Lives Matter (BLM) movement during the height of the pandemic with the tragic killing of the African-American George Floyd, due to police brutality on 25 May 2020, gave another layer of understanding the pandemic as 'racialised'.¹⁷ These events redirected examination of the role of structural racism in society, including within healthcare services, an issue that particularly affects people with SCD.¹⁸ It is against this background that we conducted our study. We wanted to delineate the psychological impact of a racialised pandemic on people with SCD and give a voice to patients' perspectives of what shielding had been like during these times. While we hypothesised that shielding could have physical benefits, we thought that mental health would be negatively impacted and wanted to understand the relationship.

METHODS

Study design

The study, conducted from June 2020 to June 2021, used a sequential exploratory mixed-methods design¹⁹ to understand the social and psychological impact of the COVID-19 pandemic on people with SCD and their carers. For the initial quantitative phase of the study, we used a modified version of the SF36 V.2, which is a health-related quality of life (HRQoL) measure (ie, physical health, mental health and role limitations), which has been validated for use in the UK.²⁰ The SF36 V.2 has been used successfully with people with SCD before in England²¹ and globally²²⁻²⁴ indicating good reliability and validity. In order to further qualitatively explore some of the psychological and social issues from the perspectives of people with SCD, the qualitative phase of the study drew on interpretive phenomenological analysis (IPA) to collect and analyse a small sample of semistructured experiential interviews. IPA has been used successfully before with this population group to understand experiences of pain,²⁵ a common symptom of SCD.

Patient and public involvement

We coproduced this project with two voluntary sickle cell organisations: OSCAR Birmingham and OSCAR Sandwell. We began by piloting questions to ask about shielding experiences, exploring with our stakeholder partners as well as a person with SCD how to best collect demographic data.

Participant population

Participant recruitment was led by the voluntary sector partners. An information sheet was provided by the research team and made available to potential participants ahead of participation on a secure website.²⁶ Information about the study was also made available through social media sites such as Twitter and Facebook. Sampling was opportunistic but directed towards people with SCD

over 18 years of age and carers of children with SCD. Interested participants could contact the voluntary sector partners or researchers. The information about the study was also repeated on the first page of the survey, and participation was anonymous and voluntary.

There was no payment for participation in the survey, but a randomised raffle gave a gift monetary voucher to three participants, if they wished to be included. If participants opted to undertake a semi-structured interview, they could also leave their contact details for the researchers confidentially at the end of the survey. Recruitment was through the survey and through the voluntary sector. Participants who did an interview were given an information sheet before any interviews and had time to ask the voluntary sector and/or researchers about the study. Participants also signed a consent form before the interview commenced and were given a 30-pound gift voucher. Fifty-one participants completed the survey, and eight took part in the semistructured interviews.

Survey development

A modified version of the SF36 V.2, was used for the quantitative phase of the research. The SF36 V.2 is a general HRQoL questionnaire, which includes 36 items to assess eight aspects of health: general health, physical functioning, physical role functioning, emotional role functioning, social functioning, pain, mental health and vitality. There are two summary measures for general health and mental health. General health is separately rated using a five-point categorical scale from excellent to poor, while change in health from the previous (non-pandemic) year is rated using a five-point categorical scale from much better to much worse.

The modifications to the standard SF36 V.2 involved asking additional demographic questions (ie, age, ethnicity and gender) and open-ended questions about shielding before the standard SF36 V.2 questions. A further open-ended question about how to improve NHS care was added to the end of the survey. The wording and questions of the SF36 V.2 items were not modified in any way, and completion was undertaken anonymously. The modified survey was piloted to check for clarity and validity. The survey was also conducted over the summer months when people with SCD are usually in better health. This was before the second wave of COVID-19 in England.

Semi-structured interview

Interviews were conducted at several points throughout the pandemic and one occurred after the end of shielding to allow comparisons. Interviews lasted between 50 min to an hour and 30 min. The voluntary sector was available afterwards to offer support and refer people if needed. Interviews were conducted over Whatsapp, Zoom and Microsoft Teams, but an external recording device was used to record the audio from the interview. Recordings were deposited on password-secured computer, transcribed and anonymised before data analysis began. We

focused on how people made sense of their experiences shielding during a pandemic and thus having a smaller sample made ethical and methodological sense using IPA.²⁷

We also wanted to minimise the risk of retraumatising people with SCD and ensured counselling support via the voluntary sector.²⁸ We also invited a BEM person with SCD, who had a counselling background and understood the impact of racism,²⁸ to support with interviews. We gave participants a choice of interviewers, information sheet and took consent orally before any interview began.²⁶ One participant took up the offer to have an interview with a BEM person.

Analysis

In order to analyse the demographic data, we used SPSS, and for the SF36 V.2, the Qualtrics software programme ProCore. The use of ProCore was to give a range of scores from 0 (worst possible health) to 100 (best possible health). A Pearson's correlation was conducted for each participant's physical component summary (PCS) and mental component summary (MCS) scores, in order to determine if there was a correlation between them. SPSS was further deployed to analyse responses to other questions around demographics of participants, impact of shielding and improvements of National Health Service (NHS) services for patients with SCD.

We also used the qualitative software NVivo V.12 to analyse the open-ended questions in our survey as well as the eight semistructured interviews.²⁶ We coded the interviews using a dual hermeneutics,²⁷ meaning we coded according to how a participant made sense of their experiences and then tried to decode this thematically to understand this experience from the participant's perspective.²⁵ We checked data analysis and thematic coding with a clinical psychologist and other members of the research team to ensure interpretation was sticking closely to how participants were making sense of their experiences.²⁹ We also conducted further checks to how qualitative data correlated to our survey data^{19 26} to develop an overall picture of how participants understood the psychological impact of shielding.

Quantitative results

Participants

In total, 51 people with SCD as well as carers of children with SCD took part in the survey, and most were between the ages of 18 and 39 years. The sample was predominantly of Black Caribbean or Black African heritage. There were 34 participants with HbSS, nine with HbSC, five who were HbS beta thal, two carriers of SCD and one person did not state their status and instead put down carer. Fourteen were caring for children with SCD, and a small number (n=3) answered the survey on behalf of their children, which was indicated in age ranges under 18 years. We had an almost even split between people who were employed and those who were unemployed. The demographic information is summarised in [table 1](#).

Table 1 Demographic description of survey participants

| | |
|-------------------------------|----|
| Ethnicity | |
| Black- Caribbean | 22 |
| Black African | 20 |
| Indian | 2 |
| Any other ethnic/mixed | 4 |
| Any other (Arab) | 1 |
| Any other | 1 |
| Missing | 1 |
| Gender | |
| Female | 39 |
| Male | 11 |
| Other | 1 |
| Employed | |
| Yes | 26 |
| No | 25 |
| SCD variant | |
| HbSS | 34 |
| HbSC | 9 |
| HbS beta thal | 5 |
| Sickle cell carrier | 2 |
| Unknown (carer) | 1 |
| Caring for child/ren with SCD | |
| No | 37 |
| Yes | 14 |
| Age range (years) | |
| 1–17 | 3 |
| 18–29 | 17 |
| 30–39 | 16 |
| 40–49 | 9 |
| 50–59 | 4 |
| 60–69 | 2 |
| SCD, sickle cell disorder. | |

There were eight interviews with adults with SCD with six women and two men who participated, which is outlined in [table 2](#). There was an equal split between participants whose physical health had improved or remained stable during the pandemic and those whose health had deteriorated. Three of the participants were in their 20s, three in their 30s, one in their 40s and one in their 60s. Seven of the interview participants had HbSS and one had HbSC. Four of these participants were women with SCD who had caring responsibilities for a child. Four were unemployed, two were working from home, one was furloughed and one was returning to work after a period of illness.

A one-tailed t-test was conducted as it has higher statistical power, for our smaller sample size. A one-tailed t-test indicated that PCS and MCS were found to be small but positively correlated ($r=0.259$, $n=51$, $p=0.033$). Therefore,

as the PCS scores increase, the MCS scores also increase, indicating that physical health can impact the reporting of mental health. The sample size enabled the detection of small correlational effect size ($\alpha=0.05$, $\text{power}=0.80$, $r=0.06$). HRQoL as measured using the SF36 V.2 was reported as considerably lower in this sample of patients with SCD in comparison with the general adult population. The mean levels of 10 factors are shown in [table 3](#). For comparison, scores from the SF36 V.2 are contrasted with SF36 V.2 scores from Iglesias-López *et al*²⁹ during the months of April–May 2020, when the Spanish population was placed in national isolation. Adults with SCD in our sample were in much longer period of shielding and reported poorer quality of life on all eight scales of the SF36-V.2. The scores correlated to general health, role physical, social functioning and role emotional were particularly marked. It is important to note that adults with SCD had a worse MCS compared with the PCS, indicating that mental health difficulties were of particular concern.

In the analysis of the open-ended question about shielding, which all 51 participants responded to, we found that the second most reported reason participants could not shield, after needing to go shopping (27%), was to keep hospital appointments (22.5%). When we examined the open-ended question about participants' desired improvements to NHS services, we recorded that 45 people answered. We noted: (1) needs for more understanding of SCD in services especially among front-line healthcare workers and in Accident and Emergency (A&E) departments (20%); (2) the need for better pandemic readiness in hospitals with respect to information, accessibility for SCD patients and knowledge of SCD (18%); (3) More psychological services (16%); (4) better pain management (11%); (5) empathy and listening in healthcare professionals (11%); and (6) more specialised healthcare services (9%). Except for pandemic readiness, these were all long-standing issues connected to SCD care going back decades.^{30–33}

Qualitative results

There were three main phenomena identified by IPA of the eight interviews (see [table 2](#)): (1) psychological impact of the pandemic; (2) psychologically distressing experiences in hospitals; and (3) invisibility of psychological impact of growing up with SCD.

Psychological impact of the pandemic

All participants explained that long-term shielding during a pandemic as a CEV person had an impact that slowly built up over time as the realities of what shielding meant set in.

Psychological toll

Participants reported the first negative psychological impacts when contacted by government letters, GP texts or phone calls.

Table 2 Demographic and social description of interview participants

| No. | Mental health | Health | Gender | Age | Employment | Sickle cell | Children | Support |
|-----|---------------|-----------------------------------|--------|-----|---|-------------|----------------------|---------|
| 1 | Worse | Better | Female | 30s | Yes (from home) | SS | Yes | Yes |
| 2 | Worse | Worse | Female | 20s | No | SS | No | Yes |
| 3 | Worse | Stable (mild crisis) | Male | 60s | No | SS | Yes, but lives alone | Yes |
| 4 | Worse | Better | Female | 30s | Yes | SC | Yes | Yes |
| 5 | Worse | Worse | Male | 40s | No | SS | No | No |
| 6 | Worse | Worse (in general last few years) | Female | 20s | No | SS | Yes | Yes |
| 7 | Worse | Better | Female | 30s | Yes (furlough) | SS | Yes | Yes |
| 8 | Worse | Worse (this year in particular) | Female | 20s | Yes (from home but having break for health reasons) | SS | No | Yes |

But I did get quite upset when the letter about shielding... and it changed for me then. And I sort of had a feeling that I would be on the vulnerable list. And when it turned into the extremely clinically vulnerable, then I did have, yeah, I was quite upset about that to be honest. (Female, 30s, interview 1)

Despite the psychological impact of the letter, having to socially isolate and being told you were CEV, there was not much attention nor information about this from healthcare professionals, care teams nor in the letters themselves.

I was a bit disappointed with the team that they did not contact us as patients and say, 'You need to shield.' Because not everyone got their letters at the same time. (...) It would have given more weight to what was said by the government and by the GPs. So, yeah, they did not contact us until a lot later and they basically told us that we're shielding. They basically sent us a letter how to deal with mental health and

what websites to use to deal with mental health, and to use mindfulness and stuff like that, which I just thought was unhelpful. (Female, 20s, interview 2)

This was echoed by several other participants, who all stated that having digital resources was not the same as psychological support, especially as emotions became more intense as what it meant to be 'vulnerable' was understood. Respondent 1 explained:

I felt trapped and I felt like, and very scared as well, because you would hear coronavirus is killing all these people and you are on a list that says you are extremely vulnerable.

Being 'at risk' and managing 'risk'

These emotions began to heighten as people learnt more about 'risk' factors correlated to getting COVID-19 and ethnicity. Thus, respondent 4, who was in her 30s, stated, 'When it started coming through that BAME people were more affected, I felt like that's almost like double whammies. I've got sickle cell and I'm Black!'. All participants were open about feelings of 'fear', 'anxiety' and 'stress'. They also discussed the consequences of 'their shielding' on family members who had to take extreme precautions to keep them safe or who also had to stay inside and shield, such as children. Respondent 1 noted:

I have had times when I have just felt so, so fed up and feeling like almost like there is nothing to look forward to, just like stuck in this, and really bad feelings of guilt as well for my daughter and my husband.

Getting through the pandemic was described as a 'challenge', 'struggle', 'hard' or to be 'managed', and parenting during a pandemic was especially difficult with no respite. In interviews, children were viewed as 'adapting', but the effects on parents was described as cumulative. Respondent 7, in her 30s, who had been looking after her child with family support explained, 'It's been really hard.

Table 3 Mean scores for each aspect of the SF36 V.2 in comparison

| Scale | SCD (n=51) | Spanish sample (n=225) |
|----------------------------|------------|------------------------|
| Physical component summary | 40.83 | N/A |
| Mental component summary | 36.19 | N/A |
| General health | 38.69 | 63.29 |
| Physical functioning | 40.18 | 84.30 |
| Role physical | 36.99 | 57.61 |
| Bodily pain | 41.14 | 66.99 |
| Vitality | 41.88 | 53.44 |
| Social functioning | 32.17 | 65.75 |
| Role emotional | 33.77 | 56.30 |
| Mental health | 39.68 | 60.47 |

Psychologically, I think it's kind of mentally damaging'. The two single men who we interviewed, despite having family and friends, described being 'isolated' and 'alone'. All participants explained how their friends and families would try to aid them to look after their physical and psychological health. Respondent 3, a man in his 60s, noted, 'I'm managing in terms of being careful wherever I go where there's a crowd, you know, I do have anxiety with that'. However, he explained that he was avoiding hospitals and any GP appointments he had.

Breaking shielding in hospitals

Hospitals were mentioned by several respondents as situations where people had to 'break' shielding and were linked to emotions of 'fear'. People with SCD did not always have a choice about having to go into hospital and symptoms like pain crises were often unpredictable. However, a respondent explained how she felt that that her 'chances of living' was linked to how she understood her identity as intersectional:

This is what intersectionality looks like, it just never stops, it was Black Lives Matter. And then it was Sarah Everard and all of the women's rights and women's protection, then it was the boys, the two sickle cell boys Richard and Evan, and how health inequalities and racial health inequalities and sickle cell and like, just having a disability. (...) I think just the fear, you heard all these things on the news saying that, actually, they're going to be rationing ICU and oxygen. So actually, if I signed up to hospital and I had a chronic illness, and he thought that I wasn't going (...), I have lower chances of living, I wouldn't be prioritised. (Female, 20s, interview 8)

Participants' reports of experiences in hospital care included lack of pandemic preparedness, lack of Personal and Protective Equipment (PPE), fears of contracting COVID-19 and stories about friends or patients with SCD being put on COVID-19 wards or getting COVID-19 and dying. They also related deaths in their communities and among their friends, but grief counselling in hospitals was never mentioned by healthcare professionals, nor was the effect of issues like BLM on patients. Respondent 2 describes this silence:

'It was never acknowledged, or discussed, like when all the stuff was going on with Black Lives Matter. Like when it first kicked off with George Floyd. There was no conversation about that, when, you know, there's been reports about how (pause) people that are Black have been treated unfairly in hospitals and been put on the COVID-ward, all that stuff, there was no discussion, there's just been no discussion nor not even acknowledgement that all of this is going on. It's like, two separate worlds.

This was not because respondents did not bring it up. Respondent 2 also poignantly explained how she brought up being affected by deaths of fellow patients with SCD:

Because even when I've brought up about mental health, with the sickle cell patients, because of the deaths and stuff, (...) the ward manager was like, 'Um, well, you know, we've had to deal with colleague deaths, as well and we have had a bad time with COVID.

The mental health needs of the staff and their emotions of fear and resentment of risking their lives was masking what was happening to patients. Yet, as respondent 3 told us, 'I've experienced death like I've never experienced it before in one year'. These stories of deaths and neglected bereavement support were often connected to their own histories and experiences of care in hospitals, which also featured narratives of death and dying.

Psychologically distressing experiences in hospitals

Data from both interviews and open-ended survey responses also highlighted participants' struggles with previous negative experiences of clinical care and how these impact their ongoing experiences with health services.

The lack of knowledge of SCD

Healthcare professionals' 'lack of knowledge' about SCD added to participants' fears of dying and concerns with 'mortality' in clinical practice became a psychological issue. Participants noted that usually they had an advocate, guardian or family member, especially mother or partner, looking after them in hospital before the pandemic. This was very important during pain crises, when patients explained losing control over their physical functioning and ability to speak or in grave situations, for instance, if they were sedated in intensive care. They felt that the presence of this person reduced bad care and acted as a guard against racist treatment. Respondent 2 explained why having an advocate was so important:

My life is in their hands (...) If I piss off that nurse, if I piss off that ward manager, or if she, even if what I am saying is correct, they just don't agree, she can delay my pain relief by half an hour, she can say that I did anything (...) there is just a lot that can go wrong in that setting. While I am a sickle cell patient, our care is not at the standard as it should be compared to other long-term health conditions that have a lot less people, because as patients we do not say anything. If we do say something, we are immediately labelled as being aggressive or whatever, so we just don't get what we should get (...) If I was white they would not see it like that (...) That is why I am so scared going into hospital during this period because we cannot have visitors.

Racism in treatment

Fears of second-class treatment, racism and being labelled as 'aggressive' were raised by other respondents. For instance, respondent 5, a man in his 40s, explained how clinical guidelines for administration of SCD pain relief

within 30 min of admission were not being met in A&E during the pandemic. He mirrors the points made by respondent 2 and explained how he tried to be agreeable and not aggressive, strategies that other patients have also engaged in to manage bad care or discrimination.³⁰ Respondent 3 also explains how he becomes ‘small’ and that is his way of dealing with the pandemic. However, this strategy of being agreeable and not aggressive could backfire as respondent 5 described:

It’s difficult because you don’t want to go against them. Like myself, because they always say, ‘Oh, (Name) is so good because he’s not like the other patients who expect the treatment and they are more strong, more assertive.’ I’m not like that. I accept things more. If they say, ‘(Name), we don’t have space.’ Or like, we give you some tablets to go home. And if you can, just go home (...) Sometimes I’ll go, but I know, I wasn’t prepared to leave yet. But because, I think like, okay, they have so many infected people on the wards.

Several respondents stated that they did not ‘go against’ the nurses or other healthcare professionals because they would then risk receiving worse care. Care became a dilemma that patients could not solve and contributed to anticipatory stress that placed participants at increased risk of having pain crises.³⁴ Generally, all participants related a link between the invisibility of pain, their ethnicity and the racism they encountered in services. Respondent 8 highlighted this when she talked about Evan Nathan Smith who died at North Middlesex University Hospital in 2019 and whose inquest was reported in the press in April 2021:

I read one of the articles about Evan and it was saying how like, basically the nurses did not believe him and didn’t believe his pain. I remember the day that they admitted me because they thought that I had the stroke. And then the nurse who admitted me was like, you can look a little bit more ill. And I was like...

Unethical treatment

Experiences of negative treatment were reported in A&E and on the wards more generally. For instance, participants related that nurses did not understand how serious illness manifests on the Black body in cases like stroke or the management of invisible pain. As stated previously, some people try to become small or agreeable, others become big and scream, but neither strategy works.

Some of the things that have been said to me and how I have been treated, like people would purposely not give me my pain relief. And then I have asked and it’s been like two hours. and I am in like excruciating pain. ‘Oh, you’ve just got a habit!’ It says two hours pain relief and I need my pain relief. She says, ‘I don’t think you are even in that much pain.’ (...) The ambulance crew picked me up one time and I was having a horrible crisis. I was screaming. The guy says to

me, ‘Shut up. Stop screaming, you’re not that much pain, it can’t be that bad.’ I was like, you can’t tell me what my pain is. You don’t have this. You’ll never understand. You don’t know how the pain feels. (Female, 20s, interview 6)

Respondent 6 illustrated the double bind that patients are in; expressions of pain for a BEM person is always too little or too much. Like other participants, she noted how racism is deeply entrenched in stereotypes of drug-seeking behaviour, yet she jokingly noted that there were places online where she could get stronger drugs. She explains that patients, and especially Black patients, are made to feel guilty for using NHS services. She notes that care can also humiliate SCD patients, reporting an instance of a nurse taking so long to help her with toileting that she had wet herself. She says the nurse’s reaction was, ‘Oh you are disgusting. You are a (age) year old! How can you be wetting yourself?’. The effects of such experiences of neglect and poor care built up, and she explains:

My mental health has been tested so much, even before COVID, it has been tested, I can’t explain it but I suppose, I like to hold things in and sometimes I do like cry about things but sometimes you get pushed over the edge.

Invisibility of psychological impact of growing up with SCD

Our participants also reported struggles with physical and psychological impacts of pain, even while they outwardly appeared healthy.

Fighting for life

In all the interviews, narratives of unethical treatment, racist experiences or loss of ability to control what was happening to them were counteracted by stories about family support, friendship among patients, care of voluntary sector and self-management of SCD. Respondents 6 and 8 each recount experiences where they had almost lost their lives in hospitals, but this was prevented by their mothers. Respondent 8, who had a life-threatening stroke during the pandemic and was treated as if she was faking it, explained how this was put in context:

My mom was like, it’s really funny, because when you were a baby, you’re probably about one, I knew something was up (...) you just weren’t right. And so, I took you to A&E at the hospital and I was like, ‘Something’s wrong with my daughter!’ and ‘Help her.’ And she’s got sickle cell and something’s wrong. And they were like, ‘She looks absolutely fine. She’s playing around. She’s doing that, she looks fine.’ And she was like, ‘No, I know my daughter!’.

In these stories, the role of the mother and child as ‘fighters’ (or ‘warriors’) who know SCD best are shared and support the necessity of a hypervigilance around hospital care. Respondent 6 has a similar story and says that her mother tells the healthcare professionals, ‘If you know my child, you would understand



this. She's always been a fighter from the day she was a baby!'. Their stories are affirming that their lives matter when lack of knowledge of SCD or racist treatment threatens those lives. Mothers are also giving their children psychological resources in a medical context where what it means to grow up with SCD, and go through traumatic and dehumanising experiences in care, is ignored.

Psychological resources

While we expected stigma related to mental health, we instead found participants remarkably astute and open. Several were seeing therapists or psychologists privately and explained that their consultants were not always aware of their diagnosis or medications. They explained psychological needs linked to bereavements, anxiety, depression, panic attacks and also experiences of racism and traumatic hospital care. One participant even suggested there should be a psychologist available for every person with SCD from childhood upwards. This is echoed by respondent one:

No, I think the main thing about mental health is, with sickle cell, it is not spoken about enough and I don't think the NHS as a whole has made enough between mental health and dealing with a chronic condition because sometimes it is just so focused on the physical and it's not accepted or considered, you kind of live in fear a lot of time. You are living in fear of getting unwell.

The fear of being in pain is also about the fear of dying, which is a message that patients with SCD are confronted with as a matter of routine. SCD is a 'taboo' or 'burden' or a 'stigma' in society and everyone shared how they were told on a regular basis that they were going to 'die' by families, communities and healthcare staff. This is reinforced by actual experiences throughout their lives when they have become ill or almost lost their lives. Respondent 4 explained:

When I had my (child), my anxiety really went sky high, because then all I was thinking about was my mortality to be to be fair, because if I had a crisis, and I passed away, who would look after him, and I think it's things that people who don't have an illness, like we do, don't think about at this age, but it's something that we do think about.

Participants related that some healthcare professionals would check in on them during the pandemic but generally they were not routinely asked about their psychological health, despite the fact that this can be a conduit to stress and thus crisis. We know that patients with SCD do not wear their conditions on their sleeves and they try to manage both their physical and psychological well-being privately.³⁵ However, while some physical needs can become visible, pain and psychological issues stayed invisible and meant that common reactions to the pandemic, like anxiety or depression, were never talked about, nor

were common emotional reactions to growing older with an uncertain chronic condition. Respondents related that if a patient was using services intensively that would trigger a clinical psychologist to talk about pain management. Patients could also self-refer to a psychologist, but it was noted that these services were typically white, not culturally affirmative nor understanding about SCD. That last point was noted as particularly important, especially if one wishes to be critical about the care received, to discuss racism or to see services improve. However, it was about more than that as respondent 2 elucidates:

I also wanted it to be someone that I could relate to, someone that was Black, that had a knowledge of the Caribbean, like the pressures of being Black in Britain, basically, and how that impacts on sickle cell and everything.

Fears and mistrust in medicine of the Black community also had to be taken seriously like being sectioned, families forced apart or being medicated. Yet, when bereavements, deaths from COVID-19 and even BLM is ignored in services, it sends a general message about who the NHS services are for and the position of BME patients in those services.

Discussion: making visible the invisible

The survey indicated that people with SCD and their carers who are undergoing long-term shielding have significant health and mental health needs that should be addressed during a pandemic. The qualitative responses to the survey and IPA analysis of interviews indicated that there is a direct connection between negative experiences of healthcare services failing to meet their needs and some of the psychological distress that people with SCD were experiencing. We feel that the following recommendations need to be addressed by NHS policy makers to improve practice for a BME population group experiencing both significant mortality and morbidity in services.

Emotional impact and funding

We initially planned to recruit 20 people for the qualitative arm²⁶ of this study, but due to demands placed on the voluntary sector, limited funding for this project and the critical issues that came out in the first two interviews touching on deaths of Black people in the NHS and BLM, we quickly realised it would be unethical.³⁶ We also noted that our voluntary sector partners were involved in offering social support during the pandemic and participating in a high volume of research studies on impact of COVID-19 on people with SCD³⁷ and BEM population group in general. We decided to slow down the pace of the research and do only what was felt to be manageable for our partners.

Education and awareness

It was noteworthy that very long-standing issues of neglect and structural racism in NHS services affecting basic

care for SCD patients going back decades³¹ were being mentioned in HRQoL survey and during interviews about psychological and social impacts of shielding. SCD is one of the most prevalent genetic disorders in England,² and it seems a matter of equity that SCD should become a part of all nursing and clinical education. During a pandemic, that education and awareness was needed in frontline staff and in Accident and Emergency (A&E) as a refresher, and safety protocols, for example, about timely pain management reiterated. However, patients were clear their treatment illuminated a bigger issue in the lack of investment in treatment and therapeutic options that they were being given as patients, instilling a second-class status.¹⁸

Especially the manifestation of pain, clinical guidelines for treatment and its invisibility seemed to be an area where there needed to be more training with racist stereotypes of drug use or fears of being too 'aggressive' still being mentioned. Participants noted delays in diagnosis,³⁸ treatment and effective pain relief putting their lives at risk. Patient strategies and dilemmas and how they affect long-term life outcomes of SCD should become part of nursing, clinical and NHS training, in particular to combat early discharge and anticipatory stress.³⁵ The self-management techniques and resources that patients had built up could be used to educate healthcare professionals, young patients transitioning to adult services as well as be a resource as per the National Institute for Health and Care Excellence (NICE) guidelines. However, there was very little co-production of resources or listening to patient expertise during the pandemic, for example, to inform preparedness or improve clinical practice.

There is also a need for more training about how serious complications like stroke can manifest in Black patients who have SCD and how signs and symptoms of conditions can manifest differently on black and other skin tones, a serious need during the COVID-19 pandemic. This has recently been addressed in NHS campaign called, 'Can you tell it's Sickle Cell?' but while such initiatives are promising more work remains to be done. In addition, we noted that there were bigger needs in the training of healthcare professionals, such as nurses, correlated to soft skills like having empathy and compassion for BME patients, even if healthcare professionals felt they were risking their lives. We wonder if there should not now be compulsory ethical training with case studies about SCD care and the impacts of racist treatment and bad care on the physical and mental health outcomes of patients and their families. People with SCD are already living with discrimination and healthcare challenges that they have to learn to navigate, with knock-on impacts on their psychological well-being, and the pandemic and shielding situation have disrupted their ability to cope with these challenges, removed sources of support and presented additional challenges. Notably, they have lost the ability to have their chosen support network help them through their interactions with services, and they are put in positions in which they have to

deal with staff who do not have an appropriate knowledge of SCD and how it might be affecting them physically and psychologically. They have to negotiate their own strategies for managing their care and making their needs known, against the background of their attempts to do so being undermined and dismissed through racist discrimination. They are doing all of this while also dealing with the anxiety of being a clinically vulnerable population concerned about COVID-19 and their own mortality.

Development of psychological support and services

The fact that patients report negative experiences of care and lack of compassion might also be a symptom of an NHS service that needs to offer more education but also care, compassion and psychological support for staff, as well as patients and their families. It was noteworthy that the general impact of long-term shielding in experiences of anxiety or depression were ignored, as well as significant psychological issues that would affect ethnic minority communities during a racialised pandemic, like bereavement support and the impact of BLM. The reason that BLM became critical to understand was because patients felt that Black lives did not matter in NHS services, and this was correlated to some of their experiences and that of their families of having to deal with 'mortality' that the pandemic amplified. Hospital experiences were also related as intergenerationally traumatic, but there were not many family-centred psychological services, outside of some London trusts, dealing with such experiences. As such, more work has to be made of training and ensuring that clinical psychologists understand SCD and that there are psychologists available who are culturally competent both for individual patients and family members such as mothers, siblings, partners or children. This cultural competence was also related to the ability to discuss impact of racism and what it means to grow up as a Black person in England. This is why some patients with SCD related going to private care - they needed to speak to a culturally affirmative psychologist who understood some of these bigger structural issues.

Psychological and social determinants of health

We wondered how to make visible some of these invisible structural issues linked to health inequalities that were impacting SCD health and psychological well-being. One potential measure to improve experience of healthcare might be the implementation of a voluntary screening tool post-COVID-19 to understand psychological and social needs of patients, so as to ensure referral of parents for respite, address experiences of racism or combat loneliness, if they wanted this. Power-Hays *et al*³⁹ have argued that this should involve looking at the wider social determinants of health like employment, housing, nutrition, education and relationships, factors that we know affect the health of a person with SCD.⁵ However, we argue services should begin with health and psychological individual well-being, then examine the wider determinants of health. In England, this has generally been the role of specialist SCD or community nurses who do build up

good relationships to patients, for example, in home visits to parents to communicate results of newborn screening. They then typically give referrals to the voluntary sector organisations or welfare and social support that exist in a local council. However, their role could be expanded to parts of the NHS where we know that there are issues, and psychological as well as social support might be needed.

Limitations

The most important limitation of this study was the small sample size of only 51 and interview size of eight participants, which were also skewed towards the female gender. A larger sample size with a more equal gender representation in multicentre SCD studies across the UK may be more representative of the total SCD community, as well as assessing mental health in relation to COVID-19 and post-COVID-19 related stressors, such as transitioning back into work or school. This study was also conducted among adults and carers of children with SCD who did not share a psychiatric diagnosis.

CONCLUSION

The previous suggestions require a long-term commitment, interventions and policy change in NHS services to ensure that Black patients' lives matter, but in the immediate going forward, it is clear that psychological support needs to be offered as a matter of routine to all SCD patients and their family members, as long-term shielding during a racialised pandemic has made visible some invisible wounds.

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