

“Ask me if I am okay”: COVID-19 and the psychological and social impact of long-term shielding experiences of people with sickle cell disorders and their care givers.



SUMMARY OF THE RESEARCH FINDINGS

INTRODUCTION

This research project was conducted from June 2020 to June 2021 during the height of the COVID-19 pandemic in the United Kingdom (UK). It was funded by De Montfort University and conducted in partnership with the voluntary sector (OSCAR Sandwell and OSCAR Birmingham) and for University Hospitals of Leicester NHS Trust.

The Midlands experienced the longest period of constant lockdown in the United Kingdom. It was also badly affected by COVID-19 with the highest deaths and numbers of ethnic minority people affected outside of London. The study took place across the Midlands region right through three periods of lockdown and during the highest level of restrictions (Tier 4 in Leicester where everything closed).

The study wanted to understand the psychological impact as well as the social needs of people with sickle cell disorders (SCD) who had been identified as 'clinically extremely vulnerable' by the government and had been asked to 'shield' at home from the 23rd of March 2020, to when shielding was officially lifted, on the 1st of April 2021. We were also interested in how parents who had SCD and parents of children with the condition were coping.

The pilot study was mixed-methods, combining a quantitative psychological survey with in-depth qualitative interviews. We adapted the SF36v2, a

questionnaire which measures health and wellbeing of people, to also ask about experiences of shielding. We also included an open-ended question at the end of the survey asking what the NHS could do to better support patients with SCD. Fifty-one people with sickle cell and carers of children gave anonymous responses online to this survey. Then we followed this up with eight key in-depth interviews and we used a psychological technique called Interpretive Phenomenological Analysis (IPA) to understand how people with sickle cell described their psychological and social needs.

KEY FINDINGS

We found that throughout the pandemic, while people's very basic social needs were being met, their psychological health needs were not. The SF 36v2 indicated that there was mental health need in people with SCD and their carers.

With our survey findings and with some interviews undertaken, we quickly adapted a policy guide around wellbeing for services during the COVID-19 pandemic: (<https://sdyson.our.dmu.ac.uk/sickle-cell-and-covid-19/>). This was to ensure policy guidance for the NHS around mental health, which health care professionals and patients with SCD and their families could use. This was at the start of the third lockdown in the United Kingdom and second wave of COVID-19.

We followed this up with the rest of our interviews at key points during shielding and after it had ended when people were getting vaccinated. We noted that, in the survey and interviews, there were three

key themes; first, about impact of shielding and pandemic response; second, how shielding was not possible for a patient group that has to access medical care and lastly, about psychological impact of the pandemic and SCD.

SHIELDING DURING THE PANDEMIC

When the government made the announcement that people with SCD were 'clinically extremely vulnerable' it was rather sudden via government letter or text message from GP. People would have liked some time to prepare and there was some distrust. Some people stated that the UK government had never taken SCD seriously. In the beginning, they also struggled to find information about what to do. Later they did appreciate accessible advice from sources like the voluntary sector, who knew their needs, as well as members of their care team, like their hematologist.

"(The) Timescale, no time given to prepare. No chance to get food in before being notified."
(Survey)

Due to the unexpected nature of shielding, they appreciated all social support, for example, from local council or voluntary sector. They noted the need for masks, face shields, gloves and Personal and Protective Equipment (PPE), which was not initially provided. GPs also had to organize that their patients' prescriptions were delivered and people with SCD needed to ensure they had a supply of pain medication. These were often extra costs that they had to bear for themselves.

One of the biggest reasons that people had to stop shielding was to go shopping, so the food parcels during the first lockdown were very helpful. It was noted that they were not culturally specific nor geared towards dietary needs but something was better than nothing. If they needed food after the first lockdown, they had to get support from the council, voluntary sector or foodbanks. Shopping for food alongside needing baby supplies, childcare and medical care were the main reasons that people needed to interrupt shielding. Having a car offered some protection but it was noted that most people needed to take public transport.

During shielding, there was a lot of anxiety about changed social circumstances with parents, women and children particularly affected. They had to combine working at home with looking after children with a serious medical condition. Many parents of children with SCD cited that they needed some respite. People with SCD also worried about impact of shielding on their family members.

Employers often did not understand those needs nor why people who had SCD or a child with SCD could not work. Medical professionals had to intervene with letters exempting them from frontline work during the pandemic, as well as while vaccinations were occurring. People with SCD have also lost jobs and gained debts. Some needed support with how to navigate the welfare system for the first time.

“Not financially been able to shield and been forced to work to support myself or my child.”
(Survey)

There were some people who had no choice about shielding and had to work financially or lived with people who still had to work. They took extreme hygiene measures and changed entire household routines to keep safe. This was not always possible if you shared a house or your housing situation was insecure.

People with SCD who had strong relational bonds with families and friends, reported being more supported during the pandemic. Those who had routines and manageable work they could do from home with a good work and life balance, as well as partner or family to support them, reported better health.

“Support of my family and being in touch with relatives and friends through social media and video calling platforms.” (Survey)

Overall having hobbies, being creative, accessing (digital) entertainment, having outdoor space (in gardens or parks), looking after yourself through nutrition, hydration, and practices like massage or mindfulness was important. The voluntary sector, friends, family and SCD support groups as well as religious organizations, all aided people through direct physical support for social needs or organizing psychological support via phone calls, Zoom meetings or WhatsApp groups to stay connected. As the pandemic went on, we noted that shielding became stratified according to understanding of risks and need for social support.

SHIELDING AND HOSPITAL CARE

This social and psychological support was very important as the messages that people with SCD and their families received about COVID-19 was that it particularly affected Black people and those from minority ethnic backgrounds – killing them. Messages about rationing care for seriously ill, disabled or people with underlying conditions also caused serious anxiety.

“And also, if I get any virus, I'm at the bottom of the pile, like, they're not going to treat me properly, or they might delay it and then like, that would be like the end of my life” (Interview 2)

Everyone feared needing to go into hospital or to see their GP and tried to avoid it. Virtual appointments were thus appreciated but some people needed to go into hospital or see their GP in person. SCD pain and complications are unpredictable but there was little advice about pain management and when people should seek medical care. Some people with SCD also need regular blood transfusions in hospitals. Needing emergency or hospital care became a significant cause of stress.

When your condition means you need to regularly access medical care, shielding becomes an oxymoron. Thus, one key finding was that people expressed a lot of fears and worries about pain management in hospital settings. They explained historical reasons for this, in experiences of bad care, racism in services or encountering healthcare professionals

with no understanding of SCD. They felt that these situations had continued and, in some cases, had gotten worse during the pandemic. They were particularly anxious about going into hospital on their own.

“With the COVID situation, it hasn't changed. Like, what is my life? It hasn't changed much. Because the way they treat me in 2020 like is what a treatment in 2019 was.” (Interview 5)

In the past, people would generally have a family member, guardian, friend or advocate to watch over them and communicate their needs, for example, during a serious pain crisis. During the pandemic, adults with SCD were expected to have treatment by themselves, increasing feelings of risk and endangerment. When staff are seen as NHS heroes, it becomes hard to ask for better care or report bad care.

In the early stages of the pandemic, people found their fears justified with hospitals and SCD specialist services that were not prepared with lack of PPE. Communication about risk reduction, (re) location of services and safety measures in hospitals was also poor. People with SCD who had common symptoms of their condition, like fever, related how they were put on COVID-19 wards.

While safety measures and protocols improved as the pandemic went on, people with SCD who were actually accessing SCD specialist services and hospitals reported both good and bad healthcare experiences. Worryingly, it was people who had high usage of hospitals that experienced unethical care. This was from all nurses (Black and white) and

across multiple hospital settings, with reports of microaggressions, bullying, accusations of drug use and explicit racism, even in specialist SCD services. Healthcare professionals did not seem to understand that the patients with SCD that come into hospital during COVID-19 are seriously ill and need urgent care.

“Like I was crying, not just from pain but because of the way they were treating me!” (Interview 6)

It was thus reported that healthcare providers still do not understand SCD and how people psychologically and physically cope with pain and invisible forms of disability. In a high pressure and under-resourced setting, patients reported resentment from healthcare professionals who could not see the invisible effects of their condition. This resentment reportedly became racial when patients were Black. Clinical guidelines for pain management were also still not being met according to some patients, with very bad experiences in A&E.

By contrast, some people felt they could trust their haematologist but that information was slow. They also felt services were better in large hospitals that did not have specialist SCD centers. They stated that SCD is typically underfunded and they felt this impacted on provision of personalised care needed for SCD. Some patients noted better services and more choices in hospitals, for example, in London where SCD is taken as seriously as cancer. They also noted the interdisciplinary expertise was important to treat not only SCD but also interaction

to other conditions and illnesses. The expertise of figures like haematologist or sickle cell specialist nurse, as well as continuity and personalisation of care in a team, was important to ensure trust in services.

Vaccine hesitancy was linked to this lack of trust in services and not knowing how the specific vaccines would affect people with SCD. There was very little detailed advice about the differences between vaccines and their possible side-effects. The bad track record of the government during the pandemic and mistrust in medicine, meant that some people were waiting to see how others were affected before taking their vaccine. Overall, despite this hesitancy most people we interviewed had their vaccines.

PSYCHOLOGICAL HEALTH

We found that during the pandemic, some people's health improved, some people's health stayed the same and some people's health got worse. Regardless of physical health, we found that everyone's psychological health was impacted by shielding, feeling at risk and living through a pandemic. This also included family members of people who were asked to shield and who were also viewed as making psychological sacrifices. People with SCD felt guilty about the impact of shielding on children, their partners and family members.

"And yeah, that would be the main thing that I want to get across, if anyone in the NHS was reading this or listening to this, to start thinking about the support that we need, around families really." (Interview 2)

While mental health tends to be viewed as a stigmatised topic, we found the opposite with people with SCD. They were very clear about the importance of healthcare and professionals asking about both physical and psychological health, as well as how people and families were coping. This was related as very important for people who were living on their own, single mothers or whose social situation might be insecure. They appreciated the voluntary sector, GP or sickle cell specialist nurses calling them.

"Had phone call from GP on two occasions to see how I was coping during shielding and this was excellent." (Survey)

Generally, we found that while there was attention for physical health, there was not much attention in NHS services for general psychological health. Many people reported being given a leaflet, told to self-refer and were not being asked how they were psychologically coping. They also felt they could not bring up psychological support with healthcare staff who seemed like they were under psychological strain. This was different if their services were also together with those of cancer care. There psychological support was the norm.

In some places, it was reported that there were not always psychological services, or these were only accessed if someone had a lot of admissions linked to pain. People were routinely asked about stress, as that is viewed as a trigger for SCD pain. Other common mental health conditions like depression or anxiety were not talked about. We also noted services struggled with understanding psychological impact

of experiences in hospitals and what it means to live with SCD, or care for someone with SCD.

“Provide a psychologist for all sickle patients from childhood right through to adulthood.”
(Survey)

Experiences of racism and Black Lives Matter (BLM) were also not discussed. This meant that often the NHS and consultants were unaware of psychological struggles of people with SCD and their families, or even if patients had a psychological condition that was being treated through therapy or medicines. Especially the need for bereavement support was not understood in how people with SCD lost friends and how COVID-19 had affected Black communities. Some patients also explained how stereotypes and discrimination prevented them from accessing good physical healthcare but also from requesting the psychological care they had a right to.

“And I think we are too scared to say, as patients if we feel like we need it because we don't want them to, like think that we're depressed or crazy for some more tablets or section us, so you know, all these things that like, you have worries especially in the Black community, that's what we kind of think about the extreme, that if we admit that we're not coping that these are all the things that they're going to do.” (Interview 2)

Several people reported having to pay for private services or accessing ineffectual psychological support in the NHS or through their GP. It was noted that psychological services that were culturally

affirmative, as well as understood SCD and impact of racism were needed. Those that were accessing private services that had those things, felt empowered and better able to cope. There was a need for short, medium as well as long-term psychological services, as well as those focused on families.

“My mental health actually hasn't come into question in any of my appointments.”
(Interview 4)

CONCLUSION

The psychological impact and social sacrifices of people who have been deemed 'clinically extremely vulnerable' are still ongoing. Many people with SCD and their families are still shielding and taking precautions as the COVID-19 pandemic is not over.

While a lot of improvements in health services have been made, we noted the need for better health and social care services. There were also serious individual reports about racism and unethical nursing care, as well as pain management clinical guidelines not being met. That is unacceptable and those issues in NHS care need to be urgently tackled. It is those issues that also led to bad psychological health and real fears of dying in hospital during the COVID-19 pandemic.

Overall, there is a silence about impact of the pandemic on seriously ill patients from minority ethnic groups needing NHS services. This has not been understood by the NHS and it is imperative that they and

their families get psychological support if needed. More worrying is the unexplored nature of impact of bad care in NHS and generally what it means to have a rare genetic condition as minority ethnic person in the UK.

RECOMMENDATIONS

Recommendations for Policy Makers

“Hospitals in 2020, they still don't understand what sickle cell is, and what the conditions are!” (Interview 4)

- Sickle cell is a leading genetic condition in England. Obtain up-to date figures from NHS England. For example, at the time of writing there were 15,000 people with SCD, meaning this is the leading genetic condition but this is not reflected in health nor social care response.
- It is important to prepare health and social care services for the impact of the pandemic which will continue post-COVID. This has to be done in a timely manner with adequate information and resources given to people to shield, as well as recover.
- The voluntary sector is an important resource and it is crucial to liaise with them to understand the needs of people with SCD and their families. This should ensure better pandemic preparedness and that information is circulated in a timely manner. These services also need better financial support.
- It is important that hospital services are informed about the wellbeing needs of patients with SCD and their families.

We have listed some of the important things we have learned from patients that need to become a part of policy and practice around wellbeing in NHS: (<https://static1.squarespace.com/static/5e8ca9bcda00561f349fa870/t/5fdc9286113da4610cac1a8b/1608290951792/Sickle+Cell+and+Wellbeing.pdf>).

- More attention also has to be given to how Black and minority ethnic patients and staff have experienced this pandemic with Black centred psychological care a matter of practice and routine.
- If there is another period of shielding or lockdown, it is important to have psychological resources in place for healthcare professionals, patients and their families, as well as children, who are routinely overlooked. These resources should not just be virtual in nature or only for serious psychological conditions.
- Access to physical healthcare as well as psychological healthcare should be a given. This should be a routine in services and through the GP, especially for people who are shielding with serious health conditions and their families.

“Nurses (should be) better trained to be humanitarians and less discriminative.” (Survey)

- There is a wider issue of ensuring diversity and understanding of invisible forms of illness and disability that affect minority ethnic patients. It is essential that SCD is part of all nursing,

clinical and also now critical ethics training in the UK.

- Unacceptable experiences of racism, unethical care and the flouting of clinical guidelines have been reported in NHS services. Widespread anxiety about pain management continues and needs to be addressed to build trust.

"I think that the A&E departments have to do more short courses in management sickle cell anaemia crises." (Survey)

- There are particular sites in the NHS where care is being experienced as negative and this is in interactions with nurses on all wards and in A&E. More nursing education on SCD and further training in these areas needs to be urgently engaged in. Patients with SCD who enter into an ambulance or A&E must be swiftly identified to ensure pain relief.

Recommendations for Health Care Professionals

- Ensure that you are looking after your physical and psychological health, as patients report that professionals who attend to their own mental health needs give them better care and are more empathetic.
- If you are GP and have an SCD patient in your care, do ensure you ask about psychological wellbeing for the patient and also their family members.
- Family members and especially young carers can be routinely overlooked by healthcare professionals but do ask how they are coping.

"Before this happened, I was told by a nurse that I was suffering from depression, but with the covid. I have had no chance to speak to someone about this." (Survey)

- If you tell a patient they have a psychological condition, or need for treatment, ensure that this is followed-up. It is important that this also occurs during a pandemic as otherwise the condition can get worse.
- Giving leaflets to patients with virtual resources or asking them if they are stressed is not checking if they are coping or providing adequate care. Do ask sensitive questions about wellbeing and psychological support. Do note that the term 'mental health' may be understood negatively but everyone is accepting that the pandemic has had a psychological impact on people.
- The pandemic has also had a social impact on patients which can lead to more stress and affect their health or social care. Do ensure that you know where to refer patients and their families.
- If the patient is Black do ensure that you know of Black counsellors, or those who understand SCD, as patients not only appreciated this, but some patients reported needing these resources during the pandemic.
- Safeguard continuity in care and a personalized response to each and every patient. SCD is complex and affects each person differently. Ensure a trusted point of contact that remains the same throughout for patients.
- Patients appreciate timely advice from trusted sources like their care team,

sickle cell specialist nurse or haematologist. Several wondered if the GP should be giving advice when the haematologist was seen as expert.

- Ensure timely information is given during a pandemic and that there is a point of contact that a patient can easily reach in case of any issues.
- Confirm that patients are empowered around pain management and that advice is shared about their pain management techniques. Inform them clearly when and how they should come to a hospital setting.
- Be aware of how to treat pain in timely manner as this was often related as an issue. Refer to NICE clinical guidelines or those endorsed by the Sickle Cell Society:
(<https://www.sicklecellsociety.org/wp-content/uploads/2018/05/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-in-the-UK-2018.pdf>).

Recommendations for Psychologists

“What we’ve learned this year is just the importance of cultural awareness in mental health as well. So, it’s really important to be able to talk to someone who gets it.” (Interview 8)

- There is a need for provision of psychological services for people who have been long-term shielding and caring for themselves or someone else with a serious medical condition. However, those services have to understand SCD and be culturally informed.

- Family members of people with SCD and children with SCD and their siblings have been neglected in psychological services and provision. It is important to ask about their wellbeing and provide services for them too.
- If a person with SCD lives with a family member who has a mental health condition, it is important to get individual and holistic support for the family.
- Do ensure that you are aware of SCD and treat the impact of the condition as well as any psychological issues that a person may have linked to hospital care or shielding during a pandemic.
- Typical issues that came up during the pandemic and experience of shielding, were depression and anxiety. Do ensure more resources around common psychological responses to a pandemic, as well as long-term periods of shielding.

Patients and Families

- There is overall increased anxiety, especially in young people during the pandemic, even without considering the additional risks for people with SCD. It is normal to need psychological support and the first point of contact is usually your GP.
- You can also ask to be referred for psychological support in a hospital setting. You may want to talk to a professional. Sometimes you may just want someone to listen.
- As a parent or caregiver of a child with SCD, you can ask for psychological or social support. This will help you be a

better parent and give your child good care. It is important to ensure your best physical and psychological health and that of your child. Sometimes the support is short-term, medium-term or long-term and does not impact how you are as a parent.

- If you are caring for a family member or parent with SCD and/or a mental health condition, or if you have SCD and are helping to care for someone with a disability or mental health condition, there is support available for you. Do discuss this with your GP or with a healthcare professional.
- The physical and psychological experience of caring and of young carers is often neglected but during and after a pandemic, it is normal to want to get some extra social or psychological support. Some people have stated that it has been helpful to be linked to other people in the same situation to talk about common experiences and what support exists.
- If you are the partner or family member of someone with SCD (inclusive of sibling), you will have also experienced some distressing situations in hospital or while coping with long-term shielding, it is normal to want to talk about these experiences and you can bring this up with your GP or sickle cell specialist nurse. Sometimes even a short chat with a professional on the phone can be helpful. The voluntary sector can also aid with resources in this area.

“They could just be there you know. Even like a five min chat, it makes a lot of difference, just to see how someone is.” (Interview 7)

Further Information:

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