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AN INVESTIGATION COMPARING CLINICIANS' KNOWLEDGE OF SICKLE CELL DISEASE

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ABSTRACT

Introduction: Sickle Cell Disease (SCD) is a common inherited haemoglobinopathy with significant oral and systemic implications. Despite its prevalence in multi-ethnic populations in the UK, there is limited evidence on clinicians' awareness and understanding of the condition. This study aimed to compare the knowledge of doctors and dentists regarding SCD, including awareness of at-risk populations, disease features, and clinical management.
Methods: A questionnaire assessing knowledge and attitudes toward SCD was distributed to clinicians at Kingston Hospital (KH) and King's College Hospital NHS Foundation Trust (KCH). Data were collected between August 2023 and January 2024 using convenience sampling in divisional meetings, clinics, and via email. Responses were analysed descriptively using percentages and frequencies, with cross-tabulation performed to compare doctors' and dentists' knowledge.
Results: A total of 100 clinicians participated (64 doctors, 36 dentists). While 81% correctly identified African/African-Caribbean patients as at risk, few recognised other affected groups such as Middle Eastern (6%) or South Asian (10%) populations. Only one participant (1%) identified all correct at-risk ethnicities. Sixty-two percent correctly identified the Hb SS genotype as Sickle Cell Anaemia, with doctors performing better than dentists (78% vs 48%). Two-thirds (66%) recognised that sickle cell trait is clinically benign, with dentists demonstrating higher accuracy (74% vs 57%). Knowledge of clinical features was limited: only 34% correctly identified that iron deficiency anaemia is not a feature of SCD.
Conclusion: This study highlights variability and gaps in knowledge of SCD among doctors and dentists, particularly regarding at-risk demographics and disease features. Improving education, clinical guidance, and cultural

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awareness is essential to ensure appropriate screening, timely diagnosis, and effective management of patients with SCD.

Keywords: sickle cell disease, sickle cell anaemia, clinician knowledge, dental education, ethnic risk factors, United Kingdom, healthcare awareness

INTRODUCTION

Sickle Cell Disease (SCD) is one of the most common genetic conditions in the UK. It affects the shape and function of red blood cells, particularly when exposed to low oxygen levels. This can manifest in many ways, including haemolytic anaemia and vascular occlusion with sickle crises. According to the Sickle Cell Society (2019), it is estimated to affect 1 in every 2000 live births in England, and there are currently around 17,500 people with the disease in England.

Sickle Cell Disease is a recessive inherited condition. To have SCD, a person inherits the allele for sickle haemoglobin (Hb S). Homozygous sickle cell disease (Hb SS) is known as Sickle Cell Anaemia and is the most severe form of the disease. A person with one of the alleles for sickle cell haemoglobin (HbS) and one normal allele (HbA) is known to have the Sickle Cell trait (Hb AS) previously known as a Sickle Cell Carrier. They do not exhibit any symptoms of the disease but have a 50% chance of passing the abnormal allele to their child (NICE, 2021).

A sickle cell crisis is also known vasculo-occlusive crisis, which causes skeletal pain or avascular necrosis, usually affecting the back and limbs. Cold, dehydration, prolonged exertion, and infection can increase the risk of a crisis (NICE, 2021). There are many complications of SCD, including: respiratory complications, retinopathy, leg ulcers and renal complications (Sickle Cell Society, 2018). Common oral manifestations of SCD have been reported (Sickle Cell Society, 2018; Chekroun et al., 2019), including delayed eruption, mandibular osteomyelitis, nerve damage to the Inferior alveolar nerve, orofacial pain and aseptic necrosis of healthy teeth.

The Standards for Clinical Care of Adults with SCD (Sickle Cell Society, 2018) in the UK states that dental infections can lead to a sickle cell crisis and recommends that, in general, patients receive ‘analgesia within 30 minutes of presentation to the emergency department’ as well as ‘urgent dental care and antimicrobial therapy as required’.

Blood transfusions may be used during a vaso-occlusive crisis but can lead to the development of antibodies against red blood cells, resulting in delayed haemolytic transfusion reactions (DHTRs) (Chekroun et al., 2019). In worst-case scenarios this can lead to death. The antibodies produced can destroy the patient’s red blood cells and transfused cells, which may lead to further symptoms that imitate a vaso-occlusive crisis (Alkindi et al., 2021). Therefore, information regarding the patient’s last crisis and transfusion history should be an important part of the medical history (Harbi et al. 2020).

Neonatal screening exists in the UK for all newborn babies by the ‘heel prick test’ where a small blood sample can undergo haemoglobin electrophoresis

(NICE, 2021; Galadanci et al. 2023). Most other cases, such as if a child is born overseas, are found in childhood due to the presentation of SCD symptoms (Sickle Cell Society, 2019). Diagnosis is uncommon in adulthood, and these cases would usually be milder forms of SCD (Sickle Cell Society 2018; Lanzkron 2021).

Screening for SCD occurs when a patient is due to undergo general surgery, dental surgery and treatment, to reduce any surgical risks during care (NHS 2022). Although recommended, patients are unlikely to undergo screening for SCD for dental surgery in primary care. The current standards recommend that prior to carrying out dental treatment, liaison with the haematologist should be carried out and any treatment requiring sedation or a general anaesthetic take place in a hospital setting, with the haematology team on hand (Sickle Cell Society, 2018; Chekroun et al. 2019; Harbi et al. 2020).

Efforts should be made to reduce stress or anxiety during dental treatment, which can trigger a crisis for patients with SCD. This includes anxiety management and Inhalation sedation if indicated (preferable to intravenous sedation), as well as keeping patients warm and hydrated (Chekroun et al. 2019; Harbi et al. 2020).

SCD predominantly affects persons of African and African-Caribbean origin but can also be in persons from the Middle East, parts of India, the eastern Mediterranean, and South and Central America; as it is linked to the distribution of malaria, or migration from a malarial area (NICE, 2021). SCD affects 8% of the black community, with increasing prevalence in mixed-ethnic background families (Sickle Cell Society, 2019).

There is, however, thought to be an erroneous presumption among healthcare clinicians that this condition affects Black communities alone (Sickle Cell Society, 2019). London and the UK has a multi-ethnic population, so it is important to know how to identify and appropriately manage the condition (Lanzkron, 2021). It was therefore deemed to be important to determine the current knowledge and awareness of clinicians on SCD, to ascertain which patients are at risk of SCD and thereby should be screened; this investigation was undertaken across two hospitals in Greater London. An assessment of knowledge amongst doctors and dentists on Sickle Cell Disease has not been conducted in this manner before in the United Kingdom.

The aim of this investigation was to assess and compare knowledge of doctors and dentists to see who they think is at risk of SCD, and who they need to ask about their sickle cell status.

METHOD

A questionnaire exploring knowledge and attitudes of health care professionals regarding SCD was created, as part of a phase 1 clinical audit to assess accuracy of knowledge regarding SCD (Figure 1). This was completed across two sites; initially at Kingston Hospital (KH) for questions 1-5 and then King's College Hospital NHS Foundation Trust (KCH), at Denmark Hill and Queen Mary's

1. What is your gender?
2. What is your Specialty?
3. What is your Grade/Job Title? e.g. ST1, CT, FY2, Consultant
4. What is your Ethnic Background?
5. Which patients would you screen for Sickle Cell Anaemia (SCA)? (please state demographic including ethnic characteristics)
6. Which one is the Sickle Cell Anaemia Genotype?
    a. *Hb SC*
    b. *Hb AS*
    c. ***Hb SS***
    d. *Hb SD*
    e. *Hb AA*
    f. *Don't know*
7. When referring to persons with Sickle Cell Trait, it is CORRECT to state that they
    a. *Need monitoring and haematological treatment*
    b. *Suffer from anaemia*
    c. ***Do not have a disease but a relatively common and clinically benign condition***
    d. *Are not advised to practice physical activity*
    e. *Don't know*
8. All of the following are features of Sickle Cell Disease EXCEPT FOR
    a. *Jaundice*
    b. *Frequent Infections*
    c. *Haemolytic anaemia*
    d. ***Iron deficiency anaemia***
    e. *Biliary Calculus*
    f. *Don't know*

Figure 1. Questionnaire handed out to KH and KCH clinicians. Questions 6, 7 and 8 were added to KCH participants

Hospital, Sidcup for questions 1-8. The questionnaire was distributed to clinicians via convenience sampling by the following methods: in person at divisional meetings and clinics using a tablet with the questionnaire loaded, and via email using a QR code or a paper copy of the questionnaire. Participants were asked not to search for the answers. The Questionnaire responses were collected from August 2023 to January 2024, until 50 responses had been completed initially at KH, then after 50 responses had been received at KCH. Participants were doctors and dentists employed at either KH or KCH during 2023. Participation was voluntary, with a response rate of 25%. The project was exempt from ethical approval, after undertaking necessary checks with the respective departments.

The questionnaire was designed and piloted using Google Forms at KH. After this feedback, a validated questionnaire was used to add three further validated questions. For the last three multiple choice questions, there were five-six options per question, with only one correct answer.

Descriptive data were presented as percentages and frequencies and the numbers were rounded to 1 decimal place. Cross tabulation was used to display the relationship amongst participants responses. For purpose of analysis, Foundation Doctors and Dental Core trainees (DCTs) were classified as Junior Trainees, and all clinicians in Oral and Maxillofacial Surgery (OMFS) apart from DCTs are listed as doctors. It should be noted than in the UK, Asian generally refers to south Asian rather than east Asian. We therefore classified anyone who listed their ethnicity as Asian in the south Asian category.

RESULTS

PARTICIPANT CHARACTERISTICS

100 Participants responded to the questionnaire, 50% (*n* = 50) from KCH and 50% (*n* = 50) from KH. 59% (*n* = 59) of responses were female and 41% (*n* = 41) male. 64% (*n* = 64) were doctors and 36% (*n* = 36) were dentists. Summary of demographic results are seen in Figure 2.

Grade of Clinician: 67% were resident doctors/dentists, 15% were staff grade doctors/dentists, 18% were Consultants.

Specialty of Clinician: Participants were from a range of specialities with the most being from Oral and Maxillofacial surgery (OMFS) 17%; then Orthodontics 14%.

Ethnic Background of Participants: This varied amongst participants., with the following being the most common; White 42%, South Asian 30%, and Middle Eastern 12%. More detail can be found in Table 1.

DEMOGRAPHIC CHARACTERISTICS PARTICIPANTS IDENTIFIED AT RISK OF SCD

(Question 5): 81% (*n* = 81) of participants correctly identified patients of African/African-Caribbean ethnicity, which was 80.6% of dentists and 87.5% of doctors. Only 6% identified patients of Middle Eastern origin; 10% identified patients of certain parts of India; 9% identified patients from Eastern Mediterranean origin; 5% identified patients from South and Central American origin, which is stated in NICE guidance (NICE, 2021). 23% (*n* = 23) identified "black" patients. Only one participant (1%) identified all correct racial backgrounds, a dentist. 5% (*n* = 5) stated that they did not know who to screen. Other Categories that participants mentioned were 'immigrants/people not born in the UK' (2%).

IDENTIFICATION OF SICKLE CELL GENOTYPE

(Question 6): 62% (*n* = 31) correctly identified the correct SCA phenotype of Hb SS; 38% (n = 19) didn't know the answer or chose the incorrect answer. 24% (*n* = 12) didn't know the answer; 14% chose the incorrect answer.

Of the participants that knew the correct genotype (a total of 31 out of 50), 58% (*n* = 18) were doctors and 42% (*n* = 13) were dentists. A higher proportion of dentists did not know the correct genetic genotype. The correct Genotype of Sickle Cell Anaemia was identified by 78% (*n* = 18 of 23) of doctors and 48%

Table 1. Participant characteristics & responses

Gender	Male	41
	Female	59
	Other	0
Place of Work	KCL	50
	KH	50
Specialty	OMFS	17
	Orthodontics	14
	Foundation	8
	Emergency Medicine	8
	Oral Surgery	5
	Urology	5
	ENT	5
	General Surgery	5
	Ophthalmology	4
	Restorative Dentistry	4
	Plastic Surgery	3
	AAU	3
	Haematology	3
	Special Care Dentistry	3
	Cardiology	2
	General Medicine	2
	GP	2
	IMT	1
	Trauma & Orthopaedics	1
	ICU	1
	Obs & Gynae	1
	Anaesthetics	1
	Rheumatology	1
Speciality: Medical or Dental	Medical	64
	Dental	36
Grade/Job Title	FY1	13

(Continued)

Table 1. (Continued)

	FY2	8
	FY3	1
	DCT1	8
	DCT2	2
	JCF	3
	IMT1	1
	CT1	4
	CT2	1
	ST1	5
	ST2	5
	ST3	2
	ST4	7
	ST5	3
	ST6	2
	ST7	2
	Speciality Doctor/SAS	15
	Consultant	18
Ethnic Background	White British	34
	White Caucasian	2
	White European	1
	White Irish	1
	White Other	4
	Asian	12
	British Asian Indian	5
	Indian	7
	Bangladeshi	3
	Pakistani	1
	Afghani	1
	Arab/Middle Eastern	8
	Turkish	1
	Iranian	1
	Egyptian	1
	Kurdish	1
	Chinese	3
	South-East Asian	2
	South Asian	1
	East Asian	1
	Chito-Brazilian	1
	Black African	3
	"Mixed/Other"	3
	Prefer Not to Say	4

(*n* = 13 out of 27) of Dentists. Figure 2 illustrates the range of answers from doctors and dentists.

CORRECTLY ANSWERED/IDENTIFIED SICKLE CELL TRAIT (QUESTION 7)

66% (*n* = 33) correctly identified the correct statement that persons with Sickle Cell Trait "Do not have a disease but a relatively common and clinically benign condition"; 26% (*n* = 13) chose the incorrect answer; 8% (*n* = 4) didn't know the answer. Of the participants that knew the correct answer (33 out of 50), 39% (*n* = 13) were doctors and 61% (*n* = 20) were dentists. More doctors didn't know the correct answer. The correct Sickle Cell Trait was identified by 57% (*n* = 13 of 23) of doctors and 74% (*n* = 20 out of 27) of Dentists. Figure 4 illustrates the range of answers from doctors and dentists.

CORRECTLY IDENTIFIED SCD FEATURES (QUESTION 8)

Only 34% (*n* = 17) correctly identified Iron deficiency anaemia was not a feature of SCD; 8% (*n* = 4) didn't know the answer; 56% (*n* = 28) chose the incorrect answer; 2% (*n* = 1) did not answer at all.

Of the participants that knew the correct answer (17 out of 50), 76% (*n* = 13) were doctors and 24% (n = 4) were dentists. More dentists didn't know the

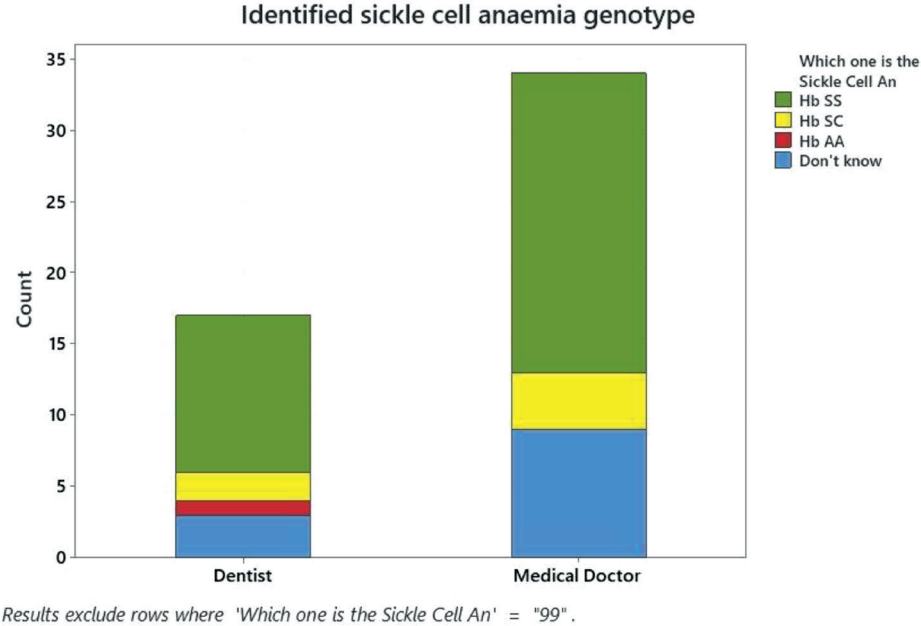

Figure 2. Correct identification of genotype comparison for doctors and dentists. The correct answer is HB SS

correct answer. The correct answers were identified by 57% (n = 13 of 23) of doctors and 15% (n = 4 out of 27) of Dentists. Figure 5 illustrates the range of answers from doctors and dentists.

A detailed summary of the Questionnaire responses is found in Table 2.

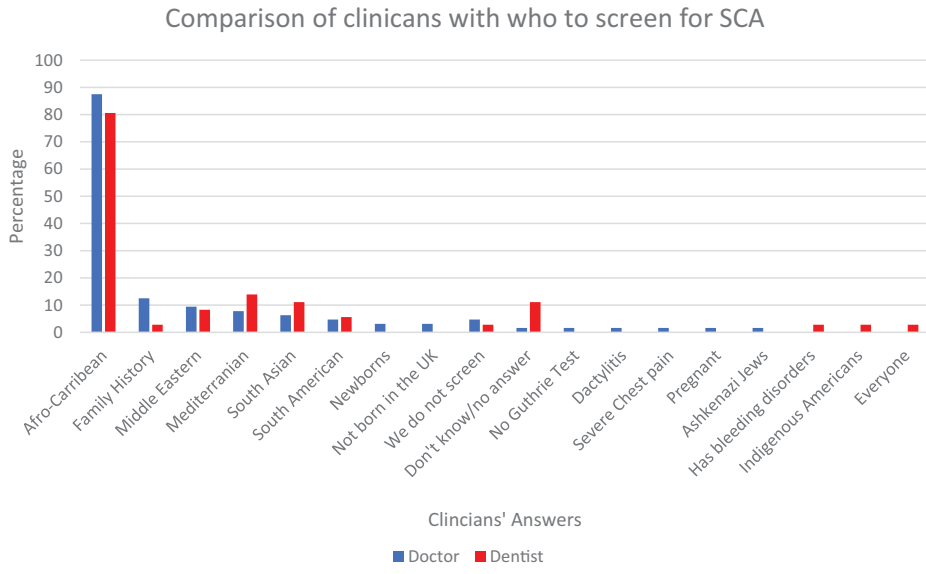

Figure 3. Clinician answers for who to screen for SCD

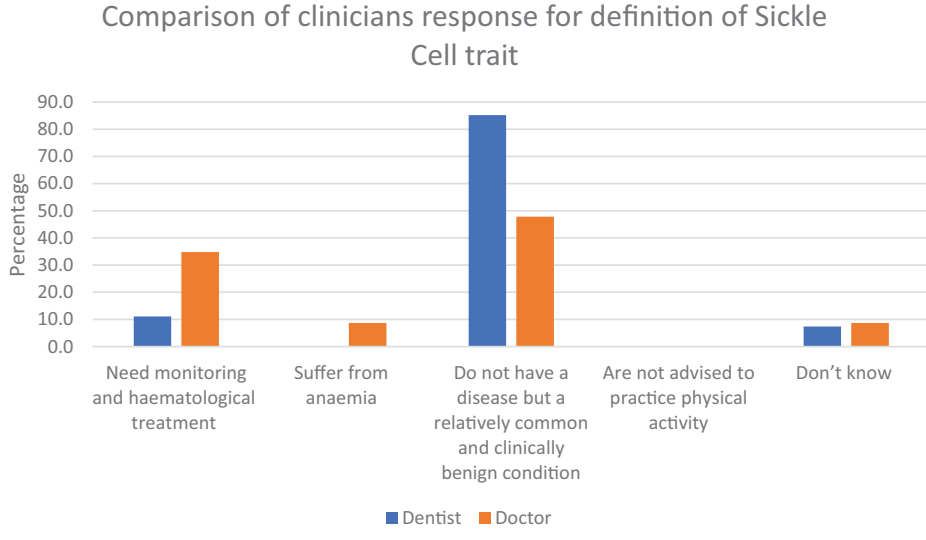

Figure 4. The correct answer is "Do not have a disease but a relatively common and benign condition"

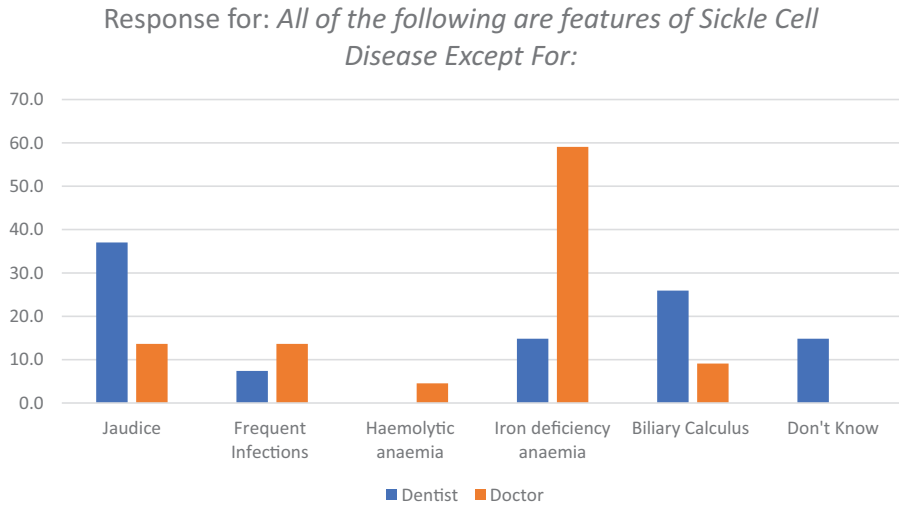

Figure 5. 27 Dentists and 22 Doctors answered. One doctor did not complete this question. The correct answer is Iron deficiency Anaemia

Table 2. Participants responses to questions

Which patients would you screen for SCD	African/African-Caribbean	81 (81%)
	India	10 (10%)
	Eastern Mediterranean	9 (9%)
	Middle Eastern	6 (6%)
	South and Central American	5 (5%)
	Indigenous Americans	1 (1%)
	Ashkenazi Jews	1 (1%)
	Family History	8 (8%)
	Immigrants/people not born in UK	2 (2%)
	Patients with bleeding disorders or history of SCD	2 (2%)
	Newborn	2 (2%)
	None	1 (1%)
	All	1 (1%)
	Don't Know	5 (5%)
	Pregnant	1 (1%)
	No Guthrie Test	1 (1%)
	Dactylitis	1 (1%)
	Severe Chest pain	1 (1%)
Correct Identification of SCD Genotype	Yes	30 (60%)
	No	20 (40%)
Correct description of Sickle Cell Trait	Yes	33 (66%)
	No	17 (34%)
Correct identification of SCD features	Yes	17 (34%)
	No	33 (66%)

DISCUSSION

Although a previous study by Ngonde et al. (2024) looked at the knowledge of clinicians outside the UK, this is the first study based on London hospitals. In order to assess validity of the population data, the participant ethnicities were compared to the wider ethnic background of the NHS. The population of Professionally Qualified NHS staff in June 2022 (n = 681,565) was reported to be white 68.7%, Asian 15.9%, Black 8%, Other 4.2%, Mixed 2.2%, Chinese 0.9% (NHS, 2023). This appears to show a disproportionately lower ethnic background from participants of a white (43%) and Black African/African-Caribbean) (3%) background at the London hospitals compared to the wider population. However, it was higher for Asian and Chinese/other Asian 5%. These proportions could be because we specifically asked dentists and doctors in our questionnaire, not the wider NHS staff professions such as nurses or pharmacists.

In the UK, National Newborn Screening Programme in the UK means that all newborns are screened for SCD (NHS, 2022). According to the NHS Sickle Cell and Thalassaemia Screening Programme (British Society Haematology, 2023), "*all babies under 1 year of age arriving in the United Kingdom should be offered screening for sickle cell disease (SCD)".* Pregnant women are not automatically offered a screening test from the NHS, unless there is a family history of the condition, or a parent has the sickle cell trait (NICE, 2022). Bain et al. (2023) recommended that patients from an ethnic group of higher Hb S prevalence should have screening pre-operatively/pre-anaesthesia. When SCD is diagnosed, education, patient counselling and management needs to be available. A study in the United States by Galadanci et al. (2023) via semi-structured interviews of healthcare professionals illustrated a lack of standardisation and high variability of management of newborn patients, after their new born screening revealed SCD.

A limitation of this study is the low response rate of less than 30 percent: it had the potential to reach hundreds of clinicians working in two sizable hospitals so this potentially limits the generalisability of the results. However, a questionnaire-based study of this type regarding SCD has not been completed before in the UK.

Multiple studies across the world have highlighted the lack of knowledge and update of SCD management recommendations and have advised the need to investigate strategies to increase uptake of education, and recommendations (Ibemere et al. (2023); Khosla et al. (2023); Moorman et al. (2023). Ancillotti et al. (2024) discussed that Dentists knowledge is varied and are unlikely to know the difference between SCD and SCA, which can also affect how they respond to questions about symptoms of the disease. They reported that in order to assess dentists' knowledge of SCA, questions should be used to check if difference between SCD/SCA. This current investigation did not ask the

difference between SCA/SCD, but it confirms that knowledge is varied amongst dentists.

Improvement in SCD knowledge is important for dentists, with Sato et al. (2011) reporting more than two thirds of patients with SCD believing that dentists lack knowledge of the disease. 40.5% of sickle cell crisis were reported to be of dental in origin, with only 20% of those reporting to be managed appropriately by their dentist.

There was great variability of knowledge about which ethnicities may be at risk of SCD. Only one participant (1%) correctly identified all patient groups listed on NICE information page (NICE, 2021). No studies reviewed this previously. SCD patients have been shown to experience barriers to care in the USA and previous studies have thought this is partly due to implicit bias amongst health care professionals held in relation to race/ethnicity in the USA (Merz et al. (2024); FitzGerald & Hurst (2017); DeLaune et al. (2020)). This has also been found in NHS care in the UK, where patients admitted to wards or presenting to emergency departments received substandard care, negative attitudes and some faced racism (FitzGerald & Hurst (2017); DeLaune et al. (2020); Mahase (2021). The NHS has recently announced a national review and improvement programme of services for patients with sickle cell disorder (SCD) and thalassaemia (Carter, 2024). This is a significant step in acknowledging this bias, recognising the need to enhance service quality, outcomes for SCD and understanding variations in care they receive and barriers to improvement (FitzGerald and Hurst, 2017).

Several factors may contribute to a lack of knowledge among dentists/doctors (Robinson et al. 2021). Unlike more widely recognized conditions, there's a paucity of guidelines or resources specifically targeting dental care for sickle cell disease patients. The absence of such information may make it harder for clinicians to feel confident in managing this condition. Developing clear guidelines for dental professionals regarding management of patients with SCD would help raise awareness and ensure such patients receive appropriate care. As well as incorporating education of the condition in both undergraduate curricula and postgraduate studies (Robinson et al., 2024). Vallely et al. (2023), tested a medical education app aimed specifically at SCD, which found use of the app improved knowledge and practice of SCD without costly face-to-face education, which could offer a possible solution.

CONCLUSION

There is significant variation in knowledge of SCD amongst hospital doctors and dentists. Patient demographics, particularly ethnic backgrounds more likely to be affected, appear to be misconceived among many clinicians. Additionally, knowledge is lacking regarding the symptoms of the condition. It is important for clinicians to understand SCD, as it allows for timely screening and treatment as necessary, as patients with SCD present to a wide range of

health care settings with specific issues and special considerations for care. Further education and dissemination of reliable information to increase awareness of SCD sufferers is required. As the UK continues to strive for equity in healthcare, it is crucial that SCD is given the attention it requires, by improving education, enhancing cultural sensitivity, increasing collaboration with other healthcare providers, and developing clear guidelines for dental care, which currently are not available. It may then be possible to improve care and reduce the burden of SCD on affected patients.

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REFERENCES

Alkindi S, Elsadek RA and Al-Madhani A et al (2021) 'Impact of COVID-19 on vasoocclusive crisis in patients with sickle cell anaemia', *Int J Infect Dis 106*:128–133.

Bain, B.J., Daniel, Y., Henthorn, J., de la Salle, B., Hogan, A., Roy, N.B.A., Mooney, C., Langabeer, L. and Rees, D.C. (2023). Significant haemoglobinopathies: A guideline for screening and diagnosis. *British Journal of Haematology*, *201*(6):1047–65. doi:https://doi.org/10.1111/bjh.18794.

Carter M (2024) 'Recruitment under way for clinician to lead national review of sickle cell disorder (SCD) and thalassaemia', Getting It Right First Time – GIRFT [Internet]. 2024 [cited 2024 Nov 23]. Available from: https://gettingitrightfirsttime.co.uk/recruitment-under-way-for-clinician-to-lead-national-review-of-sickle-cell-disorder-scd-and-thalassaemia/

Chekroun M, Chérifi H, Fournier B, Gaultier F, Sitbon I-Y and Ferré FC et al (2019) 'Oral manifestations of sickle cell disease', *Br Dent J. 226*(1):27–31.

DeLaune J, Close J and Murphy M (2020) 'Addressing bias towards patients with sickle cell disease', *Lancet Haematol. 7*(7):e508.

FitzGerald C and Hurst S (2017) 'Implicit bias in healthcare professionals: a systematic review', *BMC Med Ethics. 18*(1).

Galadanci N, Phillips S, Schlenz AM, Ivankova N and Kanter J (2023) 'Understanding gaps in current practices of newborn screening follow-up for sickle cell disease in the United States', *Blood. 142*(Supplement 1):2529–2529.

Harbi T, Harbi S, Malik M and Meligy O (2020) 'Sickle cell anemia in dentistry: manifestations and management', *Int J Med Dev Ctries. 2020:*567–71.

Helena, L., Henrique, M., Cupertino, M. and Pereira, M. (2024). Validating evidence for the knowledge, management and involvement of dentists in a dental approach to sickle-cell disease. *Brazilian Oral Research*, *38*. doi: https://doi.org/10.1590/1807-3107bor-2024.vol38.0026.

Ibemere S, Onyeka T, Ezenwosu O, Okoye HC, Ugwu N and Tanabe PJ et al (2023) 'Sickle cell disease management practices across Nigeria: A cross-sectional analysis', *Blood. 142*(Supplement 1):1143–1143.

Khosla A, Sawhney A, Hussain M, Kattel T, Shergill G and Hlaing SS et al (2023) 'Identification of risk factors for sickle cell crisis readmissions: A Community Center experience', *Blood. 142*(Supplement 1):3899–3899.

Lanzkron S (2021) 'Sickle Cell Anaemia', BMJ Best Practice. 2021 [cited 2024 Nov 20]. Available from: https://bestpractice.bmj.com/topics/en-gb/100

Mahase E (2021) 'Sickle cell disease: inquiry finds serious care failings and racism towards patients', *BMJ. 2021:*375:n2782.

Merz LE, Osei MA, Green A, Story CM, Schuering KM and Achebe MO (2024) 'Development of a hematology-general medicine hybrid team to improve care of patients with sickle cell disease', *Acad Med. 99*(6):618–22.

Moorman S, Johnson S and Raj AB (2023) 'Educating the sickle cell team about the social work role', *Blood. 142*(Supplement 1):7210–7210.

National Institute for Health and Care Excellence (NICE) (2021) 'Sickle Cell Disease Background Information', 2021 [cited 2024 Nov 22]. Available from: https://cks.nice.org.uk/topics/sickle-cell-disease/background-information/definition/

National Health Service (NHS) (2022) 'Screening for sickle cell and thalassaemia', 2022 [cited 2024 Nov 22]. Available from: https://www.nhs.uk/pregnancy/your-pregnancy-care/screening-for-sickle-cell-and-thalassaemia/

National Health Service (NHS) (2023) 'NHS Workforce by Ethnicity', 2023 [cited 2024 Nov 22]. Available from:https://www.ethnicity-facts-figures.service.gov.uk/workforce-and-business/workforce-diversity/nhs-workforce/latest/#:~:text=Summary%20of%20NHS%20workforce%20By%20ethnicity%20Summary&text=Asian%20staff%20made%20up%2012.5,down%20from%2084.1%25%20to%2074.3%25

Ngonde AM, Fina JL, Burgueno E and Lukanu PN (2024) 'Knowledge and practices of sickle cell disease among healthcare providers in Kinshasa, Democratic Republic of the Congo', *Afr J Prim Health Care Fam Med. 16*(1):e1–e8.

Robinson K, Esgro RA, Cooper S, LoPresti M and Carson B (2021) 'Identifying and addressing knowledge and confidence gaps regarding the management of patients with sickle cell disease via engaging continuing medical education', *J Hematol Oncol. 14*: 101–109.

Sickle Cell Society (2018) 'Standards for clinical care of adults with sickle cell disease in the UK', 2018 [cited 2024 Nov 22]. Available from: https://www.sicklecellsociety.org/wp-content/uploads/2018/05/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-in-the-UK-2018.pdf

Sato T, Ho H, Kiernan M, Cheng L, Naqvi Q and Imran Z et al (2011) 'Dentists' awareness of sickle cell disease—the patients' perspective', *Int J Oral Maxillofac Surg. 40*(10):1146.

Sickle Cell Society (2019) 'About sickle cell', London: Sickle Cell Society; 2019 [cited 2024 Nov 22]. Available from: https://www.sicklecellsociety.org/about-sickle-cell/

Vallely K, Proctor E, Bell K, Siddig A, Inusa BPD and Qasim A (2023) 'Sickle cell disease education in low and middle income countries using a smartphone clinical case discussion app', *Blood. 142*(Supplement 1):792–792.