Portfolio Volume 1: Major Research Project

Young People's Experiences of Being Supported with Sickle Cell Disorder Within their Educational Setting.

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Thesis submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology.

July 2026

Word count: 29291

(Excluding: acknowledgments, abstract, tables, figures, references, and appendices)

ABSTRACT

Research highlights the physical, psychological and social challenges young people with sickle cell disorder (SCD) experience in healthcare. However, there is limited research in education. This research is one of a few that explores young people's experiences with SCD in education. Semi structured interviews were conducted with five school children with sickle cell disorder in England, between the ages of 12-15.

Using interpretative phenomenological analysis (IPA), four themes emerged from the data – silently fighting an invisible illness others cannot see in school, striving for a non-totalising view of living with SCD at school, community, support and connection in education and educators adapting care according to individual need.

The findings highlighted challenges with educators making negative assumptions about participants and failing to realise their pain and discomfort. Participants described wanting to be known for aspects of their identity not related to their SCD such as their individual strengths and qualities. Support from teachers and peers who understood their needs was valued and considered important in managing at school.

This research has implications for education, community and healthcare. Such implications include training for teachers to enhance their understanding of SCD. Clinical psychologists can work collaboratively with schools to support teacher's and pupils' awareness of SCD and how to better support them. Direct psychological work with young people in the community and education is recommended. Future research is advised.

ACKNOWLEDGEMENTS

My Lord and Saviour Jesus Christ. Without you, none of this would have been possible. I thank you for sustaining me, motivating me and giving me strength at times when I felt unmotivated, unskilled and weak. It is not by my own doing but by your grace.

My grace is sufficient for you, for my power is made perfect in weakness."

2 Corinthians 12:9.

My family and friends for your prayers, guidance, support and encouragement. For encouraging me to keep going, supporting me with recruitment and checking in on my research. I'm very grateful.

To the five wonderful young people who took time to take part in my research. I am very grateful for your involvement. Your stories left me with a deep sense of appreciation and sadness, but I was inspired by the strengths you have. Your stories have left me wanting to do more and to advocate for young people with SCD in all capacities.

Thank you to the research consultants who helped to shape this research with your ideas, feedback and support. I really appreciate it.

To Dr Megan Maidment and Dr Angela Kirby. Thank you both for helping me to shape this research. Thank you for supervision, the meetings and reading my drafts.

Thank you, Megan, for uplifting me during this research when I was losing motivation.

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CHAPTER ONE: INTRODUCTION

In this section I will begin by providing a summary of my theoretical position, positionality in relation to the topic and information related to sickle cell disorder (SCD). I will discuss treatment options for SCD and SCD as a social justice issue. This will be followed by exploring the historical and current context of SCD and psychological therapies that can help understand SCD from a broader lens. Finally, I will provide an overview of the relevant literature in relation to this topic and the rationale for this current research.

1.1 My theoretical position

Epistemology refers to the theory of knowledge or ways of knowing (Edwards, 2012). This research was written from two positions. I adopted a critical realist social constructionist stance, otherwise known as "moderate constructionist" (Harper, 2011).

A critical realist ontology states that stories gathered from young people can tell us something about reality, however they do not directly mirror an objective reality (Stuchbury, 2021). For instance, for young people who discuss their experience of SCD in education, I am aware that their experience of SCD is a real experience for them, however, how it is acknowledged, experienced and communicated will vary among people over time. However, each story is valid as they are embedded within one's experiences and contexts which influence what can be known in society. While there are several structures that shape an individual's experience of SCD, such as racism, healthcare or politics, this research explores one area – education.

A social constructionist epistemology states that reality exists but cannot be accessed without social processes (Gergen, 1985). Reality is accessed through language and narratives that are available within social, cultural and historical context (Burr, 2015) and provide a shared understanding of experiences. This stance is suitable for this research as it explores how young people living with sickle cell disorder experience and make sense of their experiences within their educational setting and how they construct their narratives.

Young people with SCD interact with different individuals; educators, healthcare and families, hence this stance explores their meaning making of having SCD holding in mind their cultural beliefs, socio-economic factors and social interaction and how it might shape their experiences. SCD involves the complex lived experiences including fatigue, pain and stigma in education and healthcare. However, individual's lived experiences cannot be fully understood by looking at biomedical data only, which has traditionally been used to investigate haemoglobin levels that lead to painful crises. By understanding individual experiences, this allows one to fully understand the complex experiences of those with SCD. Next I will discuss my positionality in relation to this research.

1.2 Positionality

Positionality refers to a researcher's standpoint and worldview when conducting research (Rowe, 2014) in relation to participants and "reflects the position the researcher has chosen to adopt within a given study" (Savin-Baden and Major, 2013).

In conducting this research, it was important to reflect on my positionality. I identify as a black woman of African descent. SCD is the fastest growing genetic

condition in England, mainly affecting those from an African and Caribbean heritage (NHS, 2022). Reflecting on my identity was crucial as it shaped how I conducted this research, interpreted participant's experiences and the power dynamics at play. I considered whether race could have affected participant's trust or participants assuming we shared lived experience. With the latter, I held in mind whether participants would have expected advocacy. This was managed with reflexivity. Understanding where I hold privilege, marginalisation and power throughout the research allowed me to examine this carefully. My identity could have challenged narratives regarding who produces knowledge and adds to a field where historically black researchers were excluded in science (Essilfie-Quaye et al., 2025). While sharing my background with young people with SCD can be empowering it could also act as barrier in what or how much is shared.

I am also a Doctorate student with economic stability. Individuals with SCD in England tend to come from a lower socioeconomic background, with roughly 50% living within the 50 most deprived areas in England (Agrippa, 2022). Research highlights lower household income, lower educational outcomes and higher rates of unemployment in people living with SCD (Ozdemir et al, 2022). Highlighting class and possible differences was important as it could shape participant trust, power dynamics, disclosure and how I made sense of participants' experiences. Participants might perceive me as having institutional power, aligning with education systems and being distant from their SCD difficulties. This could lead to participants withholding negative experiences in education or modifying how they speak about their difficulties. Being reflexive throughout the research allowed me to question my assumptions and set them aside to reduce bias.

My interest in this topic stems from my personal relationship with having sickle cell trait (the presence of a single gene for sickle cell anaemia, which produces a smaller amount of haemoglobin), (NHS, 2022). Although I do not experience symptoms, throughout my upbringing the narratives I heard shaped my views and decision making. Having sickle cell trait led to curiosity regarding the experiences of those with SCD, following personal stigma attached to being a "carrier" and the racialisation of SCD. Narratives during my upbringing included me "being ok" due to not having a disorder and just a trait but the risk attached to having children. This shaped my beliefs in partner selection and the importance of disclosure. While I have sickle cell trait, my outsider status derives from not having any involvement in the sickle cell community, not having SCD, holding institutional power and being a trainee/researcher within academia. Hence, my understanding of the lived experiences of young people with SCD stems largely from research papers. This allowed me to approach the research context inherently from an outsider's perspective. While I did not intend to disclose having sickle cell trait to participants, there could have been an assumption of relatability most likely due to my race and how I responded to their experiences.

By setting my positionality, I aimed to set my personal context, ensure transparency, highlight power imbalances, decolonise knowledge and contextualise the research findings. Now that positionality has been set, I will speak about SCD.

1.3 What is sickle cell disorder?

Sickle cell disorder (SCD) is one of the most common genetic conditions affecting people in England (NICE, 2025). In England, there are around 17,000

people living with SCD – an inherited blood disorder, with 250 new cases a year. It is generally more common in people of black African, Caribbean, Middle Eastern and South Asian heritage (NHS England, 2025) and a higher prevalence among the African-Caribbean population (Sickle Cell Society, 2026). SCD is a group of inherited red blood cell disorders characterised by the production of abnormally shaped red blood cells. SCD is characterised by "sickle" shaped red blood cells that restricts the movement of the red blood cells through blood vessels limiting the delivery of oxygen (NHS, 2022). SCD can be inherited from each parent when there are two haemoglobin gene variants (NIH, 2024). Individuals with SCD experience a range of physical health challenges. This research uses "sickle cell disorder" as opposed to "sickle cell disease" which is commonly used in the medical field, following a consultation with an expert by experience. She suggested sickle cell disorder as an alternative term given the negative connotations attached to "disease". Thalassaemia on the other hand, which is mentioned in this research refers to a group of inherited conditions that affect haemoglobin. Haemoglobin does not work as well and can cause anaemia (NHS, 2022).

1.4 Impact of SCD

1.4.1 Pain

Pain episodes are one of the most common and distressing symptoms of SCD and often leads to increased hospitalisations, impacting overall quality of life (McCavit, 2012). Pain can be severe lasting for days or weeks. Pain episodes (also known as a sickle cell crisis) can affect any body part although it is most common in the back or limbs. Pain episodes vary; some might experience them once a week

while others might have less than once a year. Triggers can include the weather e.g. wind or cold, or strenuous exercise (McCavit, 2012).

Pain as a symptom of SCD is usually caused by vaso-occlusive episodes. Vaso-occlusion is the result of blockages in blood flow that restrict tissues and organs of adequate oxygen and nutrients, which results in severe pain and contributes to progressive organ dysfunction and failure (Jang et al., 2021). Recurrent episodes lead to a significant impact on the quality of life. In an outpatient paediatric haematology clinic, more than half of adolescents with SCD reported pain in the previous month in the abdomen, thorax and limbs and it interfered with daily activities for most patients (Abadesso et al., 2020). Frequent vaso-occlusive crises interfere with daily living such as missing school, work or social activities (Andoh, 2025). As well as pain, chronic fatigue is another hallmark of SCD.

1.4.2 Fatigue

Chronic fatigue refers to the overwhelming feeling of exhaustion, interfering with one's ability to perform activities and function (Ream and Richardson, 1997) and persists longer than 6 months (Korenromp et al., 2012). 65% of participants with SCD had signs of fatigue with a high intercorrelation between depression, anxiety and stress (Ahmadi et al., 2018). Besides physical health challenges, individuals with SCD are more vulnerable to infections especially when they are young.

1.4.3 Infections

Infections can range from mild e.g. colds, to much more serious and potentially life threatening, such as meningitis (NHS, 2022). To reduce the risk of infections, vaccinations and daily antibiotics such as penicillin can help. Children with

SCD are at an increased risk for bloodstream infections (BSIs). 56 (BSI) episodes in 144 patients, with a median age of 7.5 years was found (Yee et al., 2022). Despite the benefits of penicillin, compliance can be difficult to maintain. During a 7 year period, 88 children with sickle cell anaemia (SCA) who received penicillin were followed. Eight episodes of peneumococcal septicemia were found in 6 of 88 patients. In all besides one case, the children did not take penicillin at the time of the infection (Buchanan & Smith, 1986). Research shows that infections can occur after one missed dose (approx. 10-20 hours without penicillin) (Anglin et al., 1984). Besides infections, individuals with SCD can experience a range of neurological difficulties.

1.4.4 *Neurological difficulties*

SCD complications such as chest symptoms and hyperhaemolysis - a complication of blood transfusion in patients with SCD (Scottish Paediatric & Adult Haemoglobinopathy Network, 2025) - are common. There is greater screening and prevention in more economically developed countries which leads to the lower incidence of complications (Piel et al., 2013). Stroke is considered the biggest neurological complication worldwide (Kirkham & Lagunju, 2021). Epilepsy is more common in SCD compared to the general population (Ali et al., 2010). Cerebrovascular disease is another major complication in SCD with increased morbidity and mortality (Alakbarzade et al., 2023). Research highlights that silent cerebral infarction (SCI), commonly known as "silent stroke" and referring to brain tissue damage caused by a lack of blood flow, is the primary risk factor for neurocognitive deficits in those with SCD compared to those without SCI (Debaun et al., 2012).

1.4.5 Cognitive functioning

Individuals with SCD can experience memory, attention, processing speed and executive functioning difficulties. Research demonstrates an association between stroke and cognitive decline (Alpakra et al., 2024). However, research has also found that neurocognitive abnormalities can occur in children with SCD without a stroke on MRI (Farooq & Testai, 2019). The cognitive difficulties caused by SCD often affects quality of life and necessitates social support.

1.4.6 Quality of life

Individuals with SCD are at a higher risk of mental health difficulties such as depression and anxiety and a lower quality of life, due to fatigue, pain and challenges managing SCD. Challenges can be heightened by frequent hospitalisation, social isolation and the stigma surrounding SCD and mental health. Depression and anxiety were reported among those with SCA with heightened pain, low treatment adherence and disruptions to daily living. Poor quality of sleep was reported and families experienced financial difficulties, stress and social disruption. Workplace discrimination, unemployment and stigmatisation were high (Essien et al., 2023). Families and friends are considered important sources of support for those with SCD (Desine et al., 2025) and can improve health and coping for those who are severely unwell (Heinze et al., 2015). Given the impact of mental health difficulties on those with SCD, it is important to have access to social support (Bulgin et al., 2018). While social support is important, negative support in the form of stigma can affect young people's views of having SCD and their interactions with other people.

1.4.7 Perception of SCD

Younger individuals with SCD often refrain from speaking about their condition due to stigma, ridicule and the idea of being perceived as "not normal" (Winkler et al., 2023). While SCD can appear as an invisible disability, this can lead to hesitation to speak about their diagnosis (Winkler et al., 2023). Patients with less perceived personal control of SCD and higher emotional response to SCD report high social isolation, anxiety and depression and fatigue. More perceived personal control was correlated with less stress, pain, fatigue and higher mobility. Individuals with higher negative perceptions of SCD and concerns reported greater stress, depression and fatigue. Those with a better understanding of their SCD reported better self-efficacy in managing their symptoms and medication. Individuals with higher levels of stigma reported higher social isolation and self-efficacy in managing their symptoms (Winkler et al., 2023). Such difficulties related to social isolation can also occur in education. (Dyson et al., 2010).

1.4.8 Difficulties in education and Individual Healthcare Plans (IHP)

3 Some of these difficulties can be mitigated by support plans for young people.

It is a statutory requirement for schools to have individual healthcare plans (IHPs) in place to support young people with medical conditions, that is regularly reviewed and easily accessible to school staff and parents (Department for Education, 2015) An individual healthcare plan (IHP) is a document that records information about a young person's medical condition, symptoms and the support they need to get the very best from school (Well at School, 2026). An IHP can include alternative arrangements needed so a young person can fully participate in school. Including the young person's views at the centre, where they are part of the

discussion is most preferred. Schools, local authorities and health professionals should collaborate to ensure young people with medical conditions receive a full education. Supporting children to reintegrate back into school after absence may be considered. School nurses can support students and families through comprehensive care planning (Morse et al., 2021). Young people typically have access to medical support staff who is either a school nurse, school medical officer or first aider who can provide medical assistance to young people who are unwell (Department for education, 2022). Alongside IHPs in school, young people with SCD are advised to manage their symptoms by drinking plenty of fluids, dressing appropriately in the cold weather and being mindful of physical activities.

1.4.9 Self-management

The main objective of managing SCD is to reduce acute and chronic complications, which enhances the quality of life for those affected and survival (Druye et al., 2024). Self-management needs among individuals with SCD includes knowledge of SCD, emotional challenges, physical limitations and barriers to healthcare access. Additional self-management strategies include nutritional management, coping techniques e.g. regulating breathing, exercise and avoiding extreme changes in temperature and healthcare management (Druye et al., 2024). Behaviours that help prevent infections include hand washing and avoiding people who are unwell (CDC, 2024) Self-management provided by healthcare professionals typically include education, skills training and support to individuals with SCD (Druye et al., 2024). Self-management strategies are complemented well with pharmacological treatment.

1.5 SCD – Treatment

The first line of medication to reduce "sickling" of red blood cells and prevent severe symptoms of SCD is hydroxyurea. This can be recommended as a substitute for blood transfusions for children at higher risk of stroke to prevent a first stroke after a period of blood transfusions (NIH, 2024). However, in cases when children do not adhere to hydroxyurea they require a blood transfusion, which leads to missing school. Blood transfusions can treat and prevent complications.

A stem cell transplant, also known as a blood or bone marrow transplant, is considered potentially curable for SCD and requires a well-matched donor. Most transplants are done with young people who have complications such as strokes or crises (NIH, 2024).

1.6 SCD – A Social Justice Issue

When thinking about the challenges young people with SCD experience, it is important to consider this through a social justice lens. Racial disparities exist within both the healthcare and educational systems. The 'No One's Listening' report (the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG), 2021) was triggered following the death of a young black man with SCD (Sickle Cell Society, 2021). The failures made in his treatment led to the focus on the lack of understanding of SCD, the difficulties patients experience to get appropriate treatment and the consequences that can occur as a result. SCD was only recognised as a public health concern by the World Health Organisation in 2006 (World Health Organisation, 2026). Young people with SCD may lack power in advocating for themselves where their decision making is undermined, and pain is dismissed. Adolescents experience barriers to care in non-specialist hospital

settings, especially when they are alone (Miles et al., 2019). As well as the daily challenges experienced, understanding the historical context can be helpful to understand what has shaped SCD.

1.7 Historical context of SCD

SCD was first identified in the UK in the 1950s (Redhead, 2020). During the 1950s, there was huge migration from Africa and the Caribbean which contributed to the development and survival of the NHS (Snow & Jones, 2010) and the historical trajectory of SCD in the UK. As many benefitted from the NHS, people believed that migrants brought SCD into the UK. This led to hostility and racial assumptions that guided decision making in society (Redhead, 2022). As outlined by the Redhead (2022), people believed SCD was infectious which prevented black people from donating blood. People believed that black nurses in the NHS were giving SCD to their patients. Patients with SCD in hospital were labelled as drug addicts, often ignored and treated unfairly by white health care professionals, when needing medication.

Over time, initiatives were started by medical professionals which provided understanding and awareness of SCD. Black nurses were volunteers within the Sickle Cell Society. Services for SCD were created as pilots with short term funding. In 1979 the Brent Sickle Cell and Thalassaemia Centre was created. This improved the care for patients with SCD and led to courses for healthcare workers to offer counselling sensitive to individuals from ethnic backgrounds. This led to the emergence of specialists within this area (Redhead, 2022). Understanding the historical context can help to understand the current research context this research took place in.

1.8 Current research context

The data collection for this study took place between December 2025 – May 2026. In January 2025, NHS England announced a one-off gene therapy (known as exagamglogene autemcel or exa-cel) had been approved by the National Institute for Health and Care Excellence (NICE) for older children and adults with a severe form of SCD (NHS England, 2025). Clinical trials suggested that exa-cel could stop painful and unpredictable sickle cell (SC) crises. In 2024 Kendric Cromer, a 12-year-old boy from the United States was the first person to complete treatment with gene therapy for SCD, following approval from the United States Food and Drug Administration (FDA) in December 2023 (FDA, 2023). This treatment was approved for individuals 12 years and older.

Challenges exist in the availability of specialised services for SCD. A pilot specialised service was providing same day care as an alternative to A&E admissions (Crouch, 2026) and was due to close at the end of the pilot. However, in March 2026, a decision to keep this emergency unit at the Royal London Hospital was agreed following petitions.

In May 2026, a Reform MP made generic inflammatory comments about Nigerians (Halliday & Quinn, 2026). This occurred during the time of interviewing participants for this research and while it was not mentioned by participants it was important to hold in mind for context.

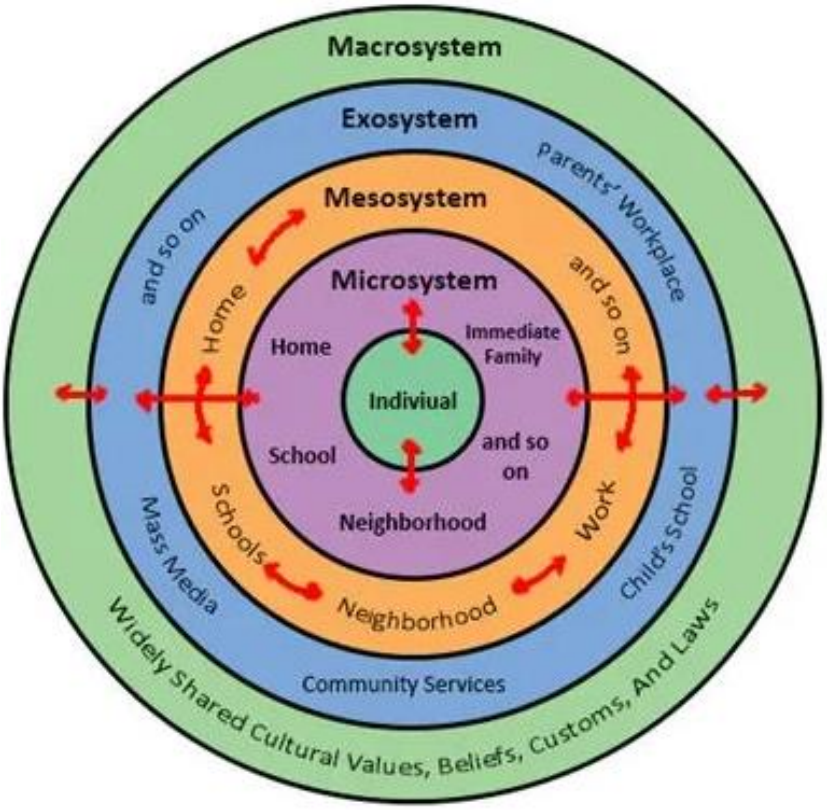
1.9 Psychological Theories

Given the historical and current research context around SCD, it is important to think about psychological theories that can help to understand SCD in the context

of systemic factors. The challenges young people experience occurs at various levels and can be affected by young people's interactions with their parents, teachers or views held by society. Theories have been proposed to understand the influence of systems on a young person's development and how young people's motivation can be influenced intrinsically and extrinsically.

One of these theories is Bronfenbrenner's ecological systems theory (EST) (Bronfenbrenner, 1979), (Figure 1) which states that a young person's development is influenced by several interconnected environmental systems such as those in their immediate environment (e.g. friends, family) to broader social influences (e.g. policies, culture or social norms). Below is a diagram of EST.

Figure 1: Bronfenbrenner's ecological systems theory (Cormac404, 2025)



The microsystem is the first level of the theory and refers to the child's immediate environment and direct relationships. The direct relationships can include

the child's family, friends, teachers and neighbours. Relationships are bidirectional which means that other people such as parents can influence the child. The child is considered an active contributor in the bidirectional interaction instead of passive.

The mesosystem is the second level of the theory and refers to the child's microsystems which do not function independently but are interrelated and influence each other. The interactions can influence a child's development. An example includes parent's inviting their child's close friends to their house which can be encouraging for the child's social support outside of school.

The exosystem comprises of social structures such as the media or local governments. The exosystem does not directly interact with the child but it influences the microsystems. For instance, if a parent's workplace did not offer flexible hours, this could lead to less time spent with their child, negatively affecting their child's development.

The macrosystem refers to how cultural factors affect a child's development such as cultural ideas, attitudes and social factors children are involved in. For instance, a family living in a recession could negatively affect their household security and the resources and opportunities available for the child.

The chronosystem refers to the transitions over time such as historical or life events. For instance, a child's parents divorcing can have a significant impact on the child's sense of identity and emotional security.

1.9.1 EST and its application to healthcare

EST has been applied to healthcare settings. Research explored ways to increase health literacy following the covid 19 pandemic across all levels of EST. An intervention on the microsystem level included health professionals engaging in

interventions targeted at individuals using simple terminology without jargon (Geboers et al., 2018). The mesosystem included staff training and enhancing the workforce (Meherali et al., 2020). At the exosystem recommendations for public funding were made to support social media, news campaigns and peer education (Zhao et al., 2023). At the macrosystem level, public policies that incentivise organisations to promote health literacy (Walters et al., 2020) were included. The integration of health systems to avoid fragmentations occurred at the chronosystem level (Dickens et al., 2025).

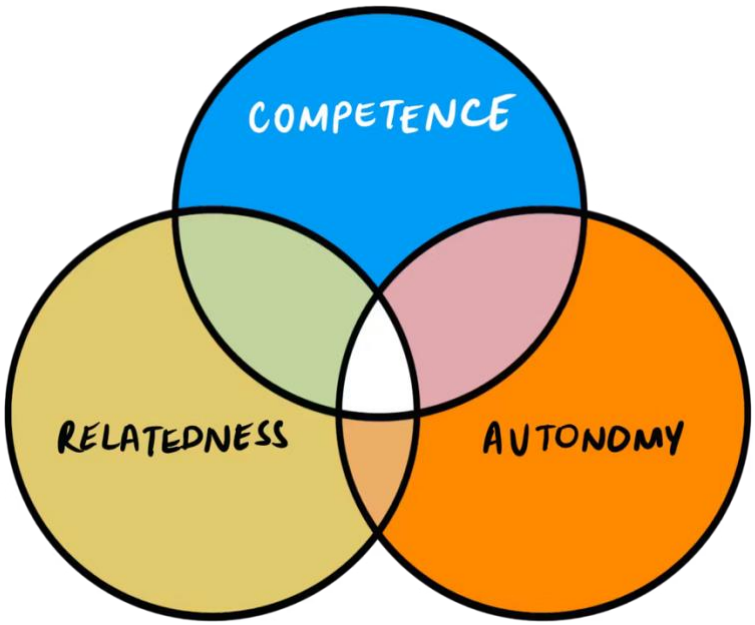
1.9.2 EST and its application to SCD

The EST has been applied to healthcare and can also be applied to understanding SCD. Young people with SCD can experience pain due to lack of water which can lead to dehydration. Access to water and reminders to remain hydrated from parents can reduce dehydration and improve wellbeing (microsystem). Young people with SCD are at increased risk of getting infections, however compliance remains challenging (Buchanan & Smith, 1986). Healthcare professionals liaising with parents to provide information about medication adherence can help young people to take medication consistently which can better manage their symptoms (mesosystem). At the exosystem, the greater incidence of screening of neurological disorders is essential to lead to less complications and less impact of young people's psychological functioning. At a macrosystem level the way in which cultures understand sickle cell, seek treatment and engage with services e.g. healthcare and education can either positively or negatively impact the access and support their child receives and how they perceive their SCD.

1.9.3 Self-determination theory

An additional theory is self-determination theory (SDT) (Deci & Ryan, 2000), which looks at human motivation and personality. It states that social context can support or prevent individual functioning based on the social environment's ability to meet individual basic psychological needs. Individuals are most motivated when their basic needs of autonomy, competence and relatedness are met. Hence, an environment which is supportive and encourages personal endeavour over pressure to feel, think or behave in a particular way is valued.

Figure 2: Self-determination theory (Kerins, 2021)



1.9.4 Self-determination theory and healthcare summary

Autonomy relates to the feeling of agency over one's life and decisions; competence refers to feeling capable in challenges and tasks and relatedness refers to the sense of belonging and security from others (Deci & Ryan, 2000). Research studies explored the relationship between self-determination theory, SDT constructs

and health behaviours such as physical activity, smoking abstinence and health indices such as depression and quality of life. Competence had direct effects on psychological and physical health (Ng et al., 2010). For instance, as feelings of competence increased, so did physical and mental health. Interventions promoting health behaviour change led to changes in autonomy support and satisfaction, competence satisfaction, relatedness satisfaction and autonomous motivation (Gillison et al., 2019).

1.9.5 Self-determination theory and SCD

Understandably the challenges of having SCD such as pain or fatigue can affect young people's motivation when their basic needs are not fulfilled. Supporting young people to understand the contributing factors to pain such as the cold weather or strenuous activities can increase competence as they are more in control of their health. Decisions regarding young people's health are often made on their behalf by parents or healthcare professionals or educators (Conway, 2026). This can reduce their autonomy; however, involving young people in their IHPs is collaborative, inclusive and encouraged for enhancing their autonomy over their health (Sanchez-Padilla, Cayuela, & Abelleira 2025). Young people with SCD may feel different from their peers due to having a condition that has a significant impact on their quality of life and school attendance (Nakubuye et al., 2026). Young people miss out on activities their friends are engaged in, lessons or tests that the majority are doing. This can affect their relatedness whereby a barrier is created between them and their peers (Nakubuye et al., 2026).

The absent voices of young people

While it is important for young people's needs to be supported. It is also important for their voices to be heard. A barrier exists between young people's voices and research which highlights a social justice issue. The voices of children and young people are often not present in research (Lenhardt, 2023) and decisions made about them do not include their voice (Kilkelli et al., 2005). They are rarely consulted on initiatives and policies that affect them (Lenhardt, 2023). Arguments exist for the preference of adults for decision making regarding children. They argue that voting rights for political parties from age 18 should be applied to decisions on population health (Ramos-Goni et al., 2020) and the ethics related to allowing young people to be involved in certain decision making is questioned (Ramos et al., 2020). While the no one's listening report (SCTAPPG, 2021) highlighted the failures of care for individuals with SCD, the voices of young people were not represented.

According to Article 12 of the United Nations Convention on the Rights of the Child, children who can form their views should have the right to freely express them in all concerns affecting them. Hence, children should be given the opportunity to be heard in all matters affecting them (General assembly resolution, 1989). In school "…children are not systematically consulted in matters that affect them", hence recommendations for the UK Government state further steps should be taken "to promote, facilitate and monitor systematic, meaningful and effective participation of all groups of children in society, including in school, for example, through school councils" (Lundy, 2009, p. 7). Save the Children's focus on climate and inequality provides an opportunity to speak to children regarding what they would like to communicate to decision makers. In doing so this amplifies children's views and supports their activism and campaigning (Lenhardt, 2023).

Summary

Young people with SCD experience physical and psychological challenges that can significantly impact their daily functioning. However, the voices of young people are often not included in research and decisions affecting their care. Typically, decisions affecting young people tend to be made by adults. This highlights the need for research where young people’s voices are at the centre of issues affecting them. To achieve this, there needs to be a better understanding of young people’s experiences of SCD from young people. Whilst there is literature that focuses on SCD in young people, it would be beneficial to summarise and synthesize what is currently known about the lived experiences of young people with SCD. The following section explores the literature on this topic.

CHAPTER TWO: SYSTEMATIC LITERATURE REVIEW

2.1 Aims and overview of the Systematic Literature Review (SLR)

This section presents the literature that is relevant to the experiences of young people with a sickle cell diagnosis/disorder (SCD). This review will provide an overview and critical evaluation of the current literature that relates to young people's experiences with SCD. This review will highlight how the findings inform the development of the current study. The research question uses "sickle cell diagnosis" instead of "disorder" to align with the language largely used in the SLR studies.

The aim of this SLR is to summarise and synthesize the relevant literature to answer the following question:

What is currently known about the lived experiences of young people with Sickle Cell Diagnosis (SCD)?

This SLR is registered with PROSPERO, the international register for prospective reviews, registration number CRD420251173582 (Appendix 1).

2.2 Systematic Literature Review Methodology

Initial searches were conducted in May 2025 and the final searches were conducted in September 2025. This was to see whether there was any new literature since the initial searches were done. Initial searches were completed via databases

such as PubMed, Science Direct and Mag Online Library. Following this, to ensure a comprehensive search, individual publishers were used to search for research that perhaps had not been captured via the databases such as Taylor and Francis. PubMed was chosen for its focus on health research. Science Direct was chosen for its broad focus on peer reviewed journals and its psychology focus. Mag Online Library was used for the search due to its focus on health literature including child health. Taylor and Francis was chosen for its comprehensive focus on science and social science publications.

2.2.1 Search Strategy

The Sample, Phenomenon of Interest, Design, Evaluation and Research Type (SPIDER) framework by Cooke et al., (2012) was used to obtain search terms. SPIDER is an effective method in managing qualitative research questions. Google Scholar and Prospero were used to confirm that a systematic review of the current research question had not already been conducted. Table 1 demonstrates the concepts used in SPIDER that were important to this research.

Search terms included operators such as "AND"/" OR" to obtain appropriate papers. The asterisk "*" function was used within search terms to widen the searches for variations of distinctive word stems such as sickle cell* which could include sickle cell disease or disorder or diagnosis or specific sickle cell variations.

Table 1

SPIDER framework for the SLR

S: Sample	P: Phenomenon	D: Design	E: Evaluation	R: Research type
Young people with sickle cell	Lived experiences of sickle cell	Semi structured interview	Experiences, beliefs, values	Qualitative

Table 2

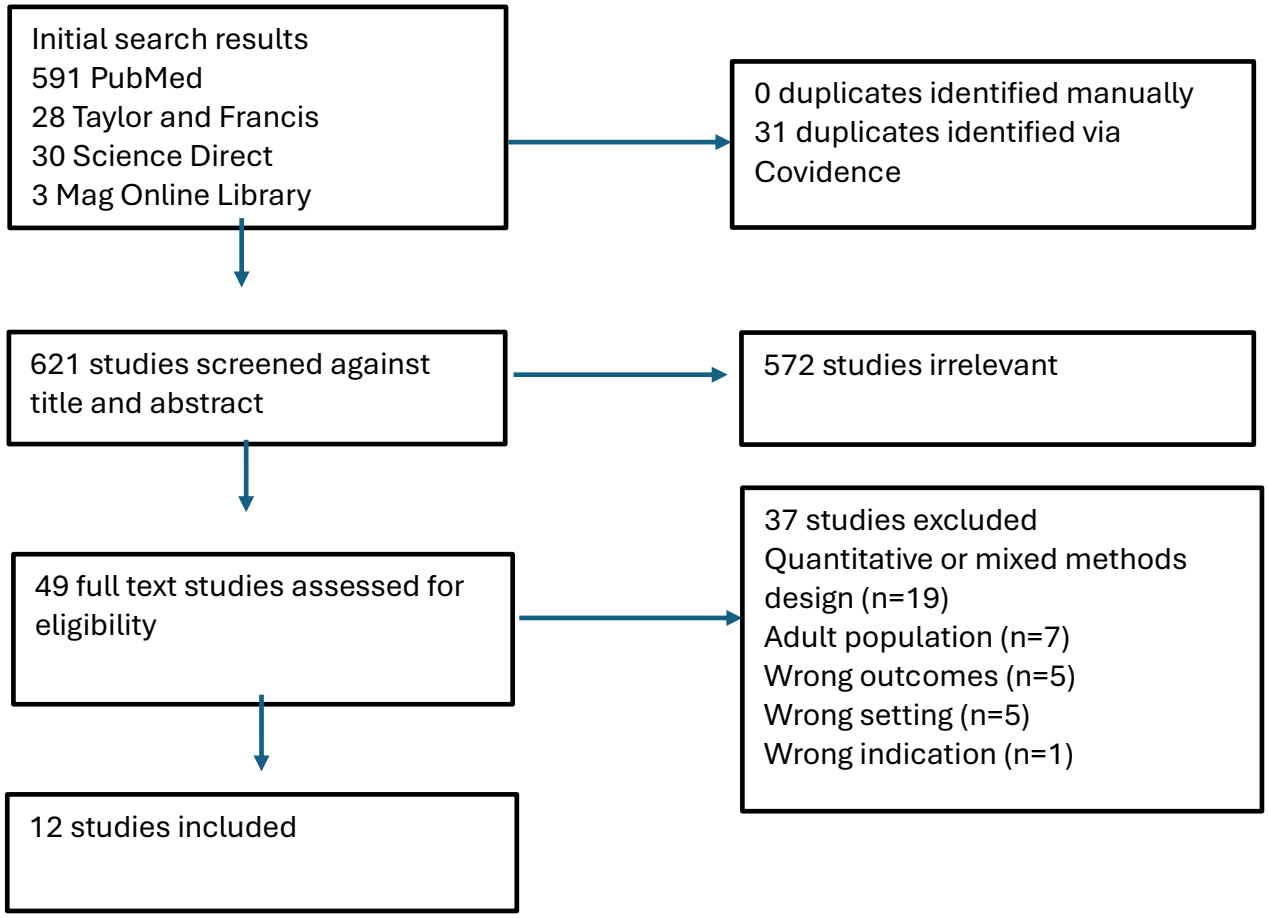
Search terms

Terms relating to related to children and young people		Terms related to Sickle Cell		Terms lived
sickle cell* OR OR lived sickle cell disease* OR OR sickle cell views* OR disorder* OR sickle cell diagnosis*	AND	Young people* OR children* OR adolescents* OR teenagers* OR youth*	AND	Experiences * experiences* impact* OR understanding*

2.2.3 Screening

One reviewer searched, screened and extracted data from the search results. The suitability of studies was discussed with the research team. For the final search, all records were imported into Covidence (Covidence systematic review software, 2023), which screened the records. Once papers had been identified, all duplicate papers were removed. Titles were reviewed for relevance to the research question, followed by reviewing abstracts and then the full text. Figure 3 demonstrates the PRISMA flow chart of all identified, included and excluded studies.

Figure 3: PRISMA flow diagram



2.2.4 Eligibility criteria

Table 3 provides the inclusion and exclusion criteria for this review. This SLR was not limited to a specific time frame to broaden the scope of studies available and to get a sense of developments or changes within young people's experiences of SCD. Despite the focus of this SLR on an adolescent population, studies with adolescents and young adults were included given the rich data and meaningful experiences. Research of adolescent brains using MRIs demonstrate that adolescence may extend to 25 years old (Arnone, 2014) and the brain does not fully mature until at least 25 years old (O'Rourke et al., 2020).

Table 3

Inclusion and Exclusion criteria

Inclusion Criteria	Exclusion Criteria
No start date – 2025	Not within this time frame.
Published in English language	Not within the English language
Peer reviewed empirical qualitative studies	Reviews or empirical quantitative or mixed methods
Studies involving a paediatric population up until 23 years old	Adult population only
Studies must include the experiences of young people, children or adolescents	Studies unrelated
Studies must include a population with a sickle cell diagnosis	Studies not inclusive of sickle cell diagnosis but speaks about thalassaemia only or sickle cell trait

2.2.5 Data Extraction

Data was extracted from each study to capture the study characteristics (see Table 4).

2.3 Results of Systematic Literature Review

The search returned a total of 652 studies. Covidence identified 31 duplicates which were removed. The remaining 621 studies were titles and abstracts screened by the researcher and out of this, 572 studies were excluded on the basis of an adult sample or quantitative or mixed methods design or a lack of focus on the experiences of SCD. The 49 full text studies were screened and 37 studies were excluded on the basis of an incorrect study design e.g. quantitative or mixed methods or non-paediatric population. This SLR included a total of 12 studies. An overview of the studies included in this SLR is in Table 4.

Table 4

Studies included in the SLR

Author, year and title	Study aim	Country	Sample	Study design and Methodology	Outcomes and key conclusions	Strengths and limitations

While & Mullen (2004) Living with sickle cell disease: the perspective of young people.	To explore the lived experience of young people with SCD as they transferred to adult services.	England	Young people with SCD (n=11). Opportunistic sample – young people attending a community-based and sickle cell and Thalassaemia centre were recruited from a caseload as they reached transition from paediatric to adult services. Six males and five females. Ages: 13–16 years (16 years: n = 2; 15 years: n = 5; 14 years: n = 3;13 years: n = 1). Most of the sample were (n = 7) Black African origin and the remainder (n = 4) were Black Caribbean. Participants were either attending school or college. Public housing (council housing: n = 4; housing association = 2), private rented or owner occupation housing (n=5).	Draft questionnaire refined through consultation and tested in a pilot study. Final questionnaire (32 closed questions and 12 open questions) assessing physical wellbeing, prophylaxis, social and emotional wellbeing. Content analysis was used for the unstructured questionnaire data for meaningful segments and sub themes and thematic analysis.	Physical wellbeing - all participants reported feeling 'fine' at the time of completing the questionnaire although two participants also reported aspects of ill-health related to fatigue. Prophylaxis - prescribed penicillin was not always taken by the sample despite its benefits. Most of the sample (n = 7) did not know why penicillin was important besides two. Social and emotional wellbeing - only one participant reported not having a good network of friends with close friends varying in number from 0–2 to more than seven.	Strengths: Questionnaire went through a consultation and was tested via a pilot study. This ensures the questionnaire is methodologically sound. Sample included a range of demographics e.g. housing and education. Limitations: Participants were reluctant to disclose their disability. Possible reasons mentioned by authors included wanting to minimise the negative stereotyping and marginalisation associated with SCD. This reluctance limits the richness of the data.
Atkin & Ahmad (2001) Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder	To provide a detailed understanding of young people's experience of living with sickle cell disorder and Thalassaemia major.	England	26 young people with SCD between the ages of 10-19. The sample was drawn from the records of health professionals in eight localities in the Midlands and Northern	Young people were interviewed twice over a 6 month period using semi structured interviews, developed through key informants and an expert advisory committee. Most young people were offered an interviewer of their own sex and ethnic background.	Young people found their illness difficult to cope with but regarded this as a natural response to their condition. Young people constantly juggled the uncertainties associated with the illness with the possibility of 'relief '. Those	Strengths: Interviews developed in consultation with others ensuring the research is methodologically sound.

			England. Males (n=12), females (n=14). sickle cell anaemia (n=18), Sickle Beta Thalassaemia (n=5), SCD (n=2) SE disease (n=1). The average age of the sample was 14.2 years. Ethnicity = 'African Caribbean' (n=19), 'mixed' (n=6) and 'Indian Hindu' (n=1). Family structure, nine young people lived with both of their 'natural' parents, four with their mother and step-father and one with foster parents. Twelve young people lived with one parent, always their mother and nine of these had regular contact with their father. Eighteen of those with SCD were still at school, five were at college and two were seeking work.		with SCD less commonly adopted the medical model. Some drew on their faith and social support. Relationships with parents were ambivalent.	Rich findings gathered. Diverse participant demographic. Young people were offered an interviewer of their own sex and ethnic background. Limitations: Analysis is unspecified.
Atoui et al., (2015) The Daily Experiences of Adolescents in Lebanon with sickle cell disease	To explore the daily lived experience of adolescents with sickle cell disease living in Lebanon	Lebanon	A purposive sample of 12 adolescents (ages 12 to 17years) with SCD who presented at the paediatric private and outpatient clinics of a tertiary care centre in Beirut, Lebanon. Males (n=5), females (n=7). Lebanese (n=6), Palestinian (n=6). All were Muslim and had been diagnosed more than 5 years ago. sickle cell Anaemia (n=11), sickle cell beta-plus thalassemia (n=1). Participants had to be pain free during the	A qualitative phenomenological methodology using a semi-structured interview. The interview guide was guided by the sickle cell and health psychology literature and in consultation with a clinical psychologist and a paediatrician. The questions addressed issues related to the experience of the disease, school, family and peer relationships, and sources of support. Thematic analysis was used.	Pain was a common theme. All had common difficulties at School with concentration difficulties, attendance and keeping up with other students. SCD restricted involvement in normal activities, creating a physical sense of isolation and social and psychological isolation. The primary support came from family. Accepting the illness as the plan of their god.	Strengths: Method is rigorous, relevant and The results are valid. Limitations: unknown whether participants who had a recent crisis and still experiencing fatigue were excluded from taking part.

			interview as assessed by the nurse.			
Clayton Jones et al., (2016). Spirituality and Religiosity in adolescents living with sickle cell disease	To provide an in-depth description of the perspectives of the participants.	America	A purposive convenience sampling from a SCD centre in a children's hospital. Participants (n=9) were approached by a research associate or clinic physician. Nine participants ranged in age from 15 to 18 years (M = 16.2). African American (n=8), African American and Sicilian (n=1). All participants attended high school. Male (n=3) female (n=6). Religious denominations included Baptist, Catholic, Pentecostal, and Presbyterian. Six were regular church attenders (3 or more times per month). Sickle cell anaemia (HbSS) (n=6), Hemoglobin S-beta-zero-thalassemia (Hbβ°/S) (n=2), hemoglobin C (HbSC) (n=1).	A qualitative descriptive design. Data were collected via a demographic survey. 24 open ended questions. participants completed two semi-structured audio-recorded interviews. Thematic analysis.	Three major themes encompassed the participants' descriptions of the relationships between spirituality/religiosity, health, and illness in their lives including spirituality/religiosity as sources for coping, influence of spirituality/religiosity beliefs on health and illness, and sharing spirituality/religiosity with HCPs. Connecting with others e.g. family provided a spiritual foundation, prayer and support especially during a crisis. Creative arts provided meaning. Connecting with God provided comfort when facing life, challenges and SCD, relying on scripture. Living according to Godly principles allowed them to live a healthy lifestyle.	Strengths: Two coders with 80% agreement highlighting inter-rater reliability. Limitations: Limited heterogeneity as participants were all African American and close in age.
Renedo et al., (2020) Understanding the health-care experiences of people with sickle cell disorder transitioning from paediatric to adult services: This sickle cell Life, a longitudinal qualitative study.	Understand health-care transitions of young people with sickle cell disorder and how these interact with broader transitions to adulthood to improve services and support.	England	Young people (n=48) (aged 13–21 years) with sickle cell disorder. Participants were recruited via sickle cell disease specialist health-care services and from communities via a network of patient advocates. (Female = 30 and Males = 18).	Longitudinal design in two English cities. Data collection included 80 qualitative interviews. 27 one-off interviews and 53 repeat interviews (i.e. interviews conducted two or three times over 18 months) with 48 participants (30 females and 18 males). An inductive approach to analysis was used and the study was co-produced with patients and carers. Inductive analytical approach, combining elements of grounded theory and thematic analysis was used. The interview schedule focused on	Key challenges relate to young people's voices being ignored. Participants reported that their knowledge of sickle cell disorder and their own needs are disregarded in hospital settings, in school and by peers.	Strengths: Recruitment occurred across two cities, hence capturing diverse participants. The drawings while talking created a more relaxed space, where the focus was moved from the young person to the drawing and what the drawing represented, potentially allowing participants to

				experiences of receiving health care, growing up and moving into adulthood, including changes experienced in life e.g. education, relationships and life at home and work.		communicate more openly. Limitations: the interview situation may have encouraged young people to present themselves through socially desirable 'modes of subjectification'.
Erskine, M. (2012). Adolescent boys with sickle cell disease: A qualitative study.	To investigate the experiences of adolescent boys with SCD.	England	Boys (n=8) aged between 13 and 17 years with sickle cell Anaemia (HbSS) via a search of their medical records. All lived at home with one or both parents and described themselves as Black African or Black Afro-Caribbean. All were practicing Christians. Five participants had severe presentations of SCD characterised by at least one painful crisis a year accompanied by other disease consequences. Three other participants had few SCD complications and less severe episodes of pain. Sampling was opportunistic.	IPA was used. Medical records were scrutinised to identify male patients aged between 13 and 17 years with a diagnosis of Haemoglobin SS disease (HbSS). The interview schedule was guided by the sickle cell and health psychology literature and developed in consultation with a young man with SCD and a Consultant Paediatrician and Clinical Psychologist. The main researcher interviewed participants in the style of an open-ended conversation guided by the semi-structured interview schedule. The schedule addressed issues of self-concept and identity, the experience of illness, family and peer relationships and sources of support.	Most participants reported pain episodes - acute or chronic. The onset was unpredictable. Strategies were used to maintain an ordinary life as adolescents. Support gained from family or medical interventions were sometimes seen as undermining their efforts to be normal.	Strengths: interview scheduled developed in consultation with a young person with SCD ensures methodological rigour. Limitations: Single centre recruitment limiting participant diversity e.g. locality or region and experience. Participants were interviewed at the hospital responsible for their health care which might have affected their ability to voice any criticisms about service delivery.
Forrester et al., (2015) The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica	To explore the lived experiences of adolescents with sickle cell disease, in Kingston, Jamaica.	Jamaica	Sampling was purposeful, n=12 adolescents (Males = 6, Females =6) with SCD, aged 18-19 years were recruited during routine visits to the sickle cell unit. Clients who met the inclusion criteria attended the sickle cell Unit within	A semi-structured interview was guided by a literature review, and probes were used to elicit rich data. Demographic data were collected, and information pertaining to their knowledge and understanding of their illness, sexual development, coping mechanisms, and support system were explored. A team of professionals, supervisors, and peers, scrutinised the items and	Most reported a positive self-concept, some expressed feeling of frustration, sadness and depression especially during painful crises, most were socially engaged. Good interpersonal relationships were reported from most, family members largely described as being supportive. Prayer and spiritual activities	Strengths: Interviews were conducted by a graduate student who had not worked with SC patients hence free of bias associated with working closely with this clientele. Pilot study to confirm the usefulness of the

			the last year and had been hospitalised for complications of SCD or had at least one emergency room visit within the last year.	determined the appropriateness of interview questions to meet the study's objective. A pilot study was conducted in a similar population, which confirmed the usefulness of the instruments.	were major coping strategies as well as family. Participants typically did not like to reveal their diagnosis of SCD to other people, especially teachers. Staying healthy to prevent painful crises.	interview. Enhances testing feasibility. Limitations: no mention of ethics or reflexivity, hence it's not clear how possible research bias was managed.
Moraes et al., (2019). Lived experiences of adolescent learners with sickle cell disease.	To explore the experiences of adolescent learners with SCD as they pursue their education.	Zambia	Purposive sampling. 5 adolescents between the ages of 13-17 years old with SCD. Participants were recruited from the university teaching hospital and were in attendance of the Friday clinic.	Semi structured interviews were used. IPA was used.	The themes included: Being sick often; grades are repeated; studies and extra lessons; Exemption from strenuous activities and teachers do not understand the condition.	Strengths: Rich and meaningful data gathered. Limitations: No mention of self-reflexivity or consultations, hence the latter may miss real world priorities.
Poku et al., (2025). "It's like going through life at a mediocre level": a qualitative study of the meaning and impact of fatigue in children and young people with sickle cell disease.	To explore the meaning and consequences of fatigue for CYP with SCD to inform services, treatments and care.	England	12 CYP between 12-23 with SCD. Convenience, snowballing and purposive sampling were used. Eight identified as female and four as male all from an African/Caribbean background. Participants were recruited from an NHS Trust in Northwest England and through SCD-focused charities (Sickle Cell Society, OSCAR Sandwell, Sickle Cell Care Manchester, and the Congenital Anaemia Network). Convenience sampling, supplemented by snowballing, was primarily employed. As the study progressed, purposive	Semi-structured interviews and art-based approaches were used. During recruitment, CYP participants were invited to engage in art-based activities, such as drawing, photography, poem writing, or creating video diaries to produce artworks related to their fatigue experiences. They selected the preferred activities and were provided with the necessary resources to complete them. These activities were to be completed in advance independently and brought to the interview for discussion. Seven CYP expressed interest in art-based methods and produced artworks. Four produced drawings and/or photographs, two produced poems and one produced a video diary. The guides and interviews focused on participants' perspectives on the meaning and impact of SCD-related fatigue in CYP; the strategies and resources used by CYP to self-manage fatigue; and current service provision for SCD-related fatigue and potential	The results found that fatigue was experienced as a constant daily struggle of reduced energy, which is invisible to others, promotes social exclusion, is difficult to manage and creates uncertainties about the future.	Strengths: Three young people with SCD were project advisors who contributed to various stages of the research e.g. recruitment and study materials, topic guides, data collection, analysis, interpretation and dissemination enhancing the rigour. Flexible data collection enhancing the comprehensiveness of data collection. Limitations: Interviews were conducted at a single time point hence do not reflect changes in fatigue. All participants were from an African/Caribbean background hence lack diversity.

			sampling was introduced.	facilitators and barriers to fatigue management in routine care.		
Poku et al., (2020). "Body as a Machine": How Adolescents With sickle cell disease construct their fatigue experiences	To examine adolescents with SCD fatigue experiences	Ghana	Participants (24 12–17-year-olds) were recruited from two SCD clinics in Ghana. Participants had no other comorbidities, were not pregnant and could communicate effectively in the English or Twi languages. Sampling included purposively sampling and theoretical sampling.	Constructivist grounded theory. Traditional interviews, drawings, photography, and picture-elicitation were used. Interviews took place either at participant's home, school, clinic, or parent's workplace. All interviews were conducted privately with the adolescents, except two where parents insisted on observing the interaction. The interviews were conducted as semi-structured conversations. The interview schedule focused on topics - the representation of fatigue; the sociocultural issues significant to fatigue experiences; the interaction between fatigue and daily functioning, identity, and social relationships; and the interactions between fatigue, identity, and self-management decisions/choices.	Adolescents with SCD spoke about their SCD through the lens of fatigue - the process of losing the energy and managing the energy daily, which was influenced by social constructions regarding childhood, youthfulness, adulthood, identity and normality.	Strengths: Multiple researchers analysed the data to ensure validity and reduce bias. The multimethod data collection approaches enhanced flexibility and the comprehensiveness of data collection. Participants were recruited from two settings to ensure comprehensiveness and credibility of the data generated. Sampling methods ensure variation in the sample and data. Limitations: Participant recruitment was done by health professionals at the research settings, which may have led to selection bias.
Poku & Pilnick (2022). Biographical accounts of the impact of fatigue in young people with sickle cell disease.	To examine the meaning of fatigue for adolescents with SCD.	Ghana	24 adolescents (12-17 years old) were recruited from two SCD treatment centres in Ghana. A purposive sampling. Males (n=12), females (n=12). Out of school (n=2); Primary school (n=5), Junior school (n=8), Senior school (n=9).	Constructivist grounded theory. Conventional face-to-face semi-structured inter-views, drawings, photography and photo-elicitation interviews. Most of the interviews occurred in participants' homes (18/24), and the rest took place in their schools (2/24) or at the clinics (4/24).	Most participants articulated their fatigue as normal. However, they articulated the fatigue they experienced as new, different and non-normal. The experience of fatigue was subjective. The meaning and significance participants attributed to their fatigue were grounded in wider societal perceptions of adolescence. Participants reported enjoying multiple and changing strategies to deal with fatigue's actual and potential biographical restriction and its stigma.	Strengths: Multi method data collection enhances comprehensiveness of the research. Self-reflexivity demonstrated during the data analysis process increases rigour. Limitations: The same participants were used in this study as well as in Poku et al 2020. This can lead to bias e.g. demand characteristics and testing effects.

Stegenga & Burks (2013). Using Photovoice to Explore the Unique Life Perspectives of Youth With sickle cell disease: A Pilot Study.	To better understand the lives of children/adolescents with SCD from their own perspective.	America	Participants with SCD (n = 12; female = 42%; 83% Hgb SS disease, 17% Hgb Sβ0 Thal) ranging from 6 to 14 years old (mean = 9.6 years) were recruited from a sickle cell clinic in a hospital prior to attending a summer camp for children/adolescents with SCD and their siblings. Potential participants were approached at the arrival of camp.	All participants were given a 27-photograph disposable camera. Qualitative interviews were conducted to share their photographs and explain the message each conveyed about their life with SCD. Interviews were content analysed and coded for salient themes related to the experience of children/adolescents with SCD. At the end of the qualitative interview, therapeutic benefit was examined through open-ended questions assessing for positive and negative aspects of the methodology. Interviews were held in a quiet, private room in the haematology/oncology clinic.	Friends were considered important; participants spoke about things to manage their symptoms such as staying hydrated. Camp was considered a valuable place where meaningful connections were made.	Strengths: Photovoice is a creative and flexible method, which allows participants to express themselves in flexible ways. Limitations: Data was collected during camp which could have limited the themes (as pictures were only restricted to camp).

2.3.1 Study Characteristics

The studies were published between 2001 and 2025 and all used a qualitative methodology. All studies recruited a cohort of individuals with SCD either attending a hospital or community clinic for their care (Atoui, et al., 2015, Clayton-Jones et al., 2016, Renedo et al., 2020, Forrester et al., 2015, Moraes et al., 2019. Six studies explicitly stated that recruitment occurred via patient's health records (While & Mullen, 2004, Atkin & Ahmad, 2001, Erskine, 2012, Poku et al., 2020, Poku & Pilnick, 2022 and Stegenga & Burks, 2013). One study recruited participants directly via hospital and SCD charities (Poku et al., 2025).

2.3.2 Study aims

All of the studies provided clear aims of their research. All studies included an adolescent population and some young adults and one study also included a younger population age 6+ (Stegenga & Burks, 2013). Eight studies aimed to explore the experiences and/or lived experiences of adolescents with SCD while others attempted to either understand the experience related to transitioning from paediatric to adult care (Renedo et al., 2020), the experience in education (Moraes et al., 2019) or the meaning making of fatigue (Poku et al., 2025, Poku et al., 2020 & Poku & Pilnick, 2022).

2.3.3 Study samples and demographics

Twelve studies were included with a total combination of 179 participants. Sample sizes ranged from 5 to 48. One study included only male participants (Erskine, 2012), one did not state the gender (Moraes et al., 2019) and the remaining 10 studies included mixed gender participants. Across the studies that used mixed

genders, there was greater representation of females. All studies reported a diagnosis of SCD and some specified the SCD variants among participants such as SCA, Sickle Beta Thalassaemia, SCD and Sickle-E disease (Atkin & Ahmad, 2001; Atoui et al., 2015; Clayton Jones et al., 2016; Erskine, 2012; Stegenga & Burks, 2013). The youngest age was 6 years old (Stegenga & Burks, 2013) and the oldest was 23 years old (Poku et al., 2025).

Eight studies included a paediatric population only and four included a paediatric and adult population (Atkin & Ahmad, 2001; Renedo et al., 2020; Forrester et al., 2015; Poku et al., 2025). Four studies reported that participants were either in education or in work (While & Mullen, 2004; Atkin & Ahmad, 2001; Clayton Jones et al., 2016; Poku & Pilnick, 2022). Despite not all studies reporting the ethnicity of participants, it appeared that most participants were black African/Caribbean. One sample was Lebanese (Atoui et al., 2015), one participant was Indian (Atkin & Ahmad, 2001) and seven participants were mixed (Atkin & Ahmad, 2011; Clayton-Jones et al., 2016). Five studies adopted consultations with an individual with lived experience of SCD to develop their questionnaire/interview and one study tested their questionnaire via a pilot study (While & Mullen, 2004). One study included experts by experience throughout the process of their research e.g. from the research design consultation to the analysis and dissemination (Poku et al., 2025).

2.3.4 Study Countries

Five out of the twelve studies took place in England (While & Mullen, 2004; Atkin & Ahmad, 2001; Renedo et al., 2020; Erskine, 2012; Poku et al., 2025). Two studies were based in America (Clayton Jones et al., 2016; Stegenga & Burks, 2013), one took place in Lebanon (Atoui et al., 2015), one in Jamaica (Forrester et al., 2015),

one in Zambia (Moraes et al., 2019) and two in Ghana (Poku et al., 2022; Poku & Pilnick, 2022). Given the variability of the study countries, this highlights the varying perspectives of individuals with SCD internationally, hence widening the scope of this SLR. The countries vary by healthcare and socioeconomic status (although there are nuances within this). In addition, given the limited studies within this field based in the UK, this highlights the need for this SLR. This SLR will allow one to gain an understanding of the experiences and needs of young people with SCD in the UK.

2.3.5 Data collection and analysis

One study used a questionnaire with 32 closed questions and 12 open questions (While & Mullen, 2004). Six studies used semi-structured interviews and interviewed participants once (Atoui et al., 2015, Clayton Jones et al., 2016; Erskine, 2012; Forrester et al., 2015; Moraes et al., 2019; Stegenga & Burks, 2013) and two studies used semi-structured interviews and interviewed participants twice (Atkin & Ahmad, 2011; Renedo, et al., 2020). Two studies used multimethod data collection methods e.g. semi-structured interviews and art-based activities such as drawing or photography (Poku et al., 2025; Poku et al., 2020; Poku & Pilnick, 2022). One study used photovoice which consisted of young people taking pictures of things that reminded them of living with SCD and being interviewed about the pictures for their meaning and story. (Stegenga & Burks, 2013).

2.3.6 Risk of Bias and Quality Appraisal

The Critical Appraisal Skills Programme (CASP), (CASP, 2024) Qualitative Checklist was used for all studies. CASP provides a framework for critically appraising studies which allows for the assessment of the study's methodological

rigour, relevance and validity. The framework presents 10 criteria that acts as markers for good quality appraisal of the methodological research. These include (1) Clear research aims, (2) Methodology (3) Design, (4) Recruitment, (5) Data collection, (6) Reflexivity, (7) Ethics, (8) Data analysis, (9) Findings, (10) Research value. Each of the studies included in this SLR have been considered against each criteria (see Appendix 2).

Across all of the studies, a high standard of quality was found among most of the criteria. However, there were some areas of weakness such as low reflexivity e.g. lack of self-reflexivity or openness about methodological challenges (Atoiu, 2015; Moraes et al., 2020;) or ethical issues e.g. no mention or limited information on ethics (Moraes et al., 2020; Renedo et al., 2020). The reasons for including these studies with the limitations included either the presence of a consultation, or the valuable insights provided by the studies and adding to the rich literature on what is currently known about the lived experiences of young people with SCD. Two studies (Poku et al., 2020; Poku & Pilnick, 2022) used the same participants, which raises concerns around bias, such as demand characteristics, testing effects and less sample diversity. Both studies were included in the review due to the different research aims and analyses, hence they made novel contributions to this topic area.

2.4 Synthesis of findings

2.4.1 Data Synthesis

A thematic synthesis of the data was completed (Thomas & Harden, 2008). Thematic synthesis consisted of line-by-line coding/ labelling and developing themes. Data was imported into NVIVO 14 (Lumivero, 2025) for this analysis. Thematic synthesis was chosen for the analysis due to its ability to build a deep

understanding from multiple studies, analytical flexibility and moving beyond describing studies to develop themes, concepts or hypotheses. For all 12 studies, initial labels were given to data, followed by adding descriptive codes. Participant quotes, text findings e.g. sections that reported on themes or author contributions and data extracts such as meaningful segments were coded in the journals. Descriptive themes and analytical themes were included. The thematic synthesis aimed to answer the review question. Seven main themes were identified, with subthemes across most themes. The themes, subthemes and quotes are demonstrated below:

2.5 THEMES

2.5.1 THEME 1: EMBODIMENT OF SICKLE CELL

Eight out of twelve studies included themes of the embodiment of SCD and spoke about concerns regarding physical appearance, pain and tiredness. The following section will demonstrate the sub themes generated with participant quotes.

2.5.1.2 Subtheme 1: Physical appearance

Participants spoke about their physical appearance "I haven't got any meat on my bones" (Erskine, 2012, p. 23) but also in relation to how other people perceived their bodies "a lot of people say about my height but I don't care. I don't take any notice of them" (Erskine, 2012, p. 23), perhaps highlighting the internalisation of external messages about SCD image. One participant said "but I would like to be taller" (Erskine, 2012, p. 23). Although it appeared that the individual did not care about their height, they stated that it was something that affected them. In addition, physical appearance was used as an indicator to predict oncoming illness "she says

when I'm going to get ill my eyes get really yellow but I don't see any difference really" (Erskine, 2012, p. 23).

Participants reported being teased due to their physical appearance, feeling tired and energy levels during sports. One participant said "…they tease me that I'm weak, girly…" (Poku & Pilnick, 2022, p. 1036). Another participant described being teased by their peers when playing sporty games and are called insults such as "incompetent" (Poku et al., 2020, p.1437).

2.5.1.3 Subtheme 2: Pain

Pain was a major theme within the studies. Participants often spoke about the pain they experienced, pain medication or other ways of managing pain. One participant said "I had pain 2 months ago and the pain was so bad I had to be hospitalized" (Atoui et al., 2015, p. 428) highlighting the severity of the pain. Another participant spoke about the unpredictability of the pain "it's mainly like when I'm out running to like, get the bus. Sometimes when I don't even run it just starts hurting" (Erskine, 2012, p. 21). Another participant described how holding the pain for too long could worsen the pain, highlighting possible pain repression.

Participants mentioned improvements in their symptoms as they got older, which appeared to be related to managing pain better or symptoms feeling more manageable. One participant said "I'm getting better as I get older" (Erskine, 2012, p. 22). Another participant spoke about pain management stating "when I was younger I think I used to, er, be in hospital a lot more [. . .] but now I'm older I can bear with it [pain]" (Renedo, 2020, p. 38).

2.5.1.4 Subtheme 3: Tiredness

Participants spoke about the impact of feeling tired or their fatigue on their health, social interactions, ability to work and mood. One participant described not wanting to "engage in any activities" (Atoui et al., 2015, p. 429) when tired and lacking energy to go out. Participants spoke about understanding why they get tired due to their red blood cell count - "I think maybe because of the low haemoglobin caused by sickle cell, that is why I get tired quickly" (Poku & Pilnick, 2022, p. 1033). When not feeling well participants said "you just want to lie down and rest" (While & Mullen, 2004, p. 322).

2.5.2 THEME 2: LACK OF INSTITUTIONAL SUPPORT

Eight out of twelve studies included themes of lack of institutional support. This consisted of subthemes such as school-related challenges and the challenges of having SCD as an employee.

2.5.2.1 Subtheme 1: School-related challenges

Participants described the challenges of having SCD and being in school such as staff failing to understand their SCD and missing school. One participant described missing a lot of school and not receiving much support from his teachers (Atoui et al., 2015) or understanding (Moraes et al., 2019). Another participant described being in a PE lesson and his teacher's response. The participant "… stopped, and then he said I had a detention" failing to realise that he could have been in pain or tired and needed support. Participants often missed school due to sickness or other SCD-related difficulties. For instance, a participant spoke about being admitted to hospital for two months and missing "the whole school term" (Poku & Pilnick, 2022, p. 1039). Missing school due to sickness was common among

young people and some participants had to repeat certain school years due to poor performance (Moraes et al.,2019).

Another participant spoke about wanting his school to understand that he would miss a lot of school, as he did in his previous school. Trying to explain to school how SCD affected them was often challenging. For instance, a participant said "you have to answer them over and over again" (Renedo, 2020, p. 45) possibly highlighting the difficulty in other people taking it seriously and trying to understand SCD and its impact. Similarly, another participant felt that "they come and ask you, next time they come and ask you again" (Forrester et al., 2015, p. 5). This often led to participants having to explain themselves. Support provided included catch up lessons and extra studies for those who had fallen behind (Moraes et al., 2019). One participant said "for my own protection, my teachers did not allow me to go to the cafeteria during lunch time or to participate in recess" (Atoui et al., 2015, p. 429).

2.5.2.2 Subtheme 2: Unsupportive work environment

Participants described difficulties having SCD at work such as colleagues failing to understand their needs and feeling pressured to push through their difficulties despite feeling unwell. Another participant spoke about being at work stating "if I'm standing up like 'cause some days it's just, it's not busy so they're like, oh you have to get off the till and whatever" (Renedo, 2020, p. 42). Another participant spoke about telling his workplace he had SCD and being told to take 5 minutes to rest if he wanted to (Renedo, 2020). Another participant spoke about being at work and others thinking "… it looks like me not wanting to do much. I guess it looks like being lazy or just putting in no effort" (Poku et al., 2025, p. 9). One participant felt that he needed to prove himself at work - "sometimes I'll be reluctant

to take time off [from work] or I'll try, or I'll just take painkillers and go rather than, erm, not going" (Renedo, 2020, p. 48). While these quotes highlight the challenges of SCD in the workplace, they also highlight the perceptions of SCD, the need to prove oneself and striving to assimilate despite having a complex physical health condition.

2.5.3 THEME 3: INTERPERSONAL RELATIONSHIPS

Nine out of twelve studies included themes of interpersonal relationships. This consisted of the benefits and limitation of friends, the challenges of family members, comparing oneself to their peers and resistance to accept their SCD and striving to be "normal".

2.5.3.1 Subtheme 1: The value of friendships

Friends were considered important sources of interaction and comfort. However, some participants thought their friends did not really understand SCD and others wanted them to understand to help them when in crisis. One participant said "and even my friends who know about it, they don't really know about it" (Renedo, 2020, p. 43). Some felt frustrated with those who claimed to "understand what [they] are going through (Atkin & Ahmad, 2001, p. 622). Having to explain oneself to their peers seemed to be difficult. A participant said "sometimes I feel like I have to explain why I can't do certain things or why I have to, um, drink so much water" (Renedo, 2020, p. 40). Some participants during art elicitation explained "we're all sitting down, talking and having fun" (Stegenga & Burks, 2013, p. 272). While this quote does not highlight SCD, it speaks to the value in friendships and a focus on something other than SCD.

2.5.3.2 Subtheme 2: The Burdens/Pressures from Family and Friends

Participants spoke about the impact of SCD on missing out on activities or social interactions with peers. One participant said "sometimes when I'm sitting alone, I see my friends playing, running, or competing in sport games, and they beg me to play with them, but I have to say no because I'm sick" (Atoui et al., 2015, p. 429). Another participant had to "…. cut down on spending time with [their] friends and engaging less in physically demanding activities with them" (Poku & Pilnick, 2022, p. 1039). Participants often reported needing to be exempted from strenuous activities (Moraes et al., 2019) due to the impact it could have on their health. Pressure to fit in, not disappoint and to conform to social norms were reported among participants. One participant said "there was the pressure to do what everyone was doing" (Poku & Pilnick, 2022, p. 1034) despite the implications on their health. Another spoke about not wanting to disappoint his friends on the sports team, saying "if I disappoint them, they'll never let me play again" (Poku & Pilnick, 2022, p. 1038). Such quotes highlight the social compromise of SCD.

Some participants felt that they had to prove themselves to others due to their SCD-related difficulties. One participant said "by then I'll have shown myself as strong and capable" (Poku et al.,2020, p. 1438). Participants sometimes pushed themselves to their limit when in social interactions to not let down their peers, even to their detriment. Another participant said "so, you push through, knowing your body will push back, but you do it anyway" (Poku et al., 2025, p. 9) highlighting that despite knowing the repercussions of overexerting themselves, they did so anyway.

Participants tended to speak about the burden of parents and although their intention was good, it was not always received well. One participant said "sometimes

I didn't go to school; not because I was sick, but because my parents prevent me from getting sick; so like if rain falls they don't send me to school" (Forester, 2015, p. 5). One parent doubted whether their child had been drinking enough water (Renedo, 2020). Having a supportive sibling was valuable and reflected as "she's always tending to my needs and is always there for me" (Atoui, 2015 et al., p. 430). Another participant spoke about having a sister with SCD and how "she tells [his] mother what [he's] really feeling" (Atoui et al., 2015, p. 430).

2.5.3.3 Subtheme 3: Social Comparisons

Participants tended to compare themselves to other people such as their peers or people their age. One participant spoke about what they can't do and what their friends are able to do and the impact on him. He said "I don't like watching people do things I can't, so I avoid these types of activities. I see my friends playing, running, and I can't even walk easily" (Atoui et al., 2015, p. 429). Another participant spoke about the limitations of their body describing it as "…some aged machine not as fit as that of my peers because I can't stand those running, jumping and ball games" (Poku & Pilnick, 2022, p. 1036).

2.5.3.4 Subtheme 4: Striving for Normality

Participants often spoke about wanting to be normal or do normal things. One participant said "…I am getting more normal as I get older" (Erskine, 2012, p. 24) and another said "they saw me as normal until that time. I felt embarrassed" when speaking about a crisis they had" (Poku et al., 2020, p. 1437). Another participant spoke about wanting to do "normal teenage things" although it is "not always possible" (Poku et al., 2025, p. 11). Some participants demonstrated resistance in

accepting their SCD diagnosis, with one participant wanting a "second opinion" (Erskine, 2012, p. 26). Another participant doubted his parents that he had SCD stating "all I do is listen, they tell me I've got it, my parents tell me I've got it … so … I believe it, but …" (Erskine, 2012, p. 25). A participant said "when I'm tired, I feel I need to continue because I want to show I'm also normal, which leads to whole-body tiredness" (Poku & Pilnick, 2022, p. 1039).

Participants demonstrated similar ideas of what it means to be a man. Although some spoke about strength, others acknowledged that while men with SCD might feel weak, caring for their family is also a sign of being a man. One participant said "when I think of a man, what comes to mind is fitness, strength and energy levels" (Poku & Pilnick, 2022, p. 1037) "…and manage to take care of yourself and your family, you're a man even though we're not strong" (Poku & Pilnick, 2022, p. 1041). This highlights the multiple roles (societal and familial) and expectations of young men with SCD.

2.5.4 THEME 4: NEGLECT AND MISTRUST IN HEALTHCARE

Eight out of twelve studies identified themes where participants described challenges in healthcare. This was a common theme across participants and focused on challenges such as staff attitudes and conduct, the busyness of A&E and participants' preference for interacting with health care practitioners (HCPs).

2.5.4.1 Subtheme 1: Limitations in Healthcare

Participants demonstrated different views regarding their experience with members of their medical team. For instance, one participant said, "and like, they're dead funny and stand-offish and because they're doctors, think they know it all, and

they don't really" (Atkin & Ahmad, 2001, p. 623) highlighting two sides of doctors. Participants did not feel able to discuss their fatigue "because [doctors] don't ask about it" (Poku et al., 2025, p. 9). There was uncertainty regarding the care received depending on the staff. For instance, one participant noted that "the nurses are different on each ward, so it depends on the nurse itself, they're gonna be mean or kind" (Renedo, 2020, p. 27).

It appeared that some participants wanted more from their doctors as advice he received was "just the same, that my mum should drop me at school and pick me up" (Erskine, 2012, p. 21). There was a sense that a participant felt the doctor perceived themself as the expert of their care as demonstrated in "they'd [doctors and nurses] always be like, yeah, you should be taking antibiotics. We know more about your condition than you" (Renedo, 2020, p. 24).

Despite the negative experiences reported by participants, some had good interactions with their medical staff. One participant reported "… [the doctor] has helped me a lot since I've been in adolescence. She has found solutions" (Poku et al., 2025, p. 11) highlighting that finding practical solutions to their concerns instead of giving the same advice was helpful.

Participants often spoke about hospital staff's insensitivity to their pain. For instance, one participant said "they didn't do anything to try and get my pain down and my mum was really upset" (Renedo, 2020, p. 54) and another participant said "maybe his pain's not that bad he just wants some morphine" (Renedo, 2020, p. 28). A participant expressed frustration regarding their pain experience. The participant said "I told some of the nurses, and there is one I'm thinking of that, I still had the pain and they were asking me if I was alright" (Atkin & Ahmad, 2001, p. 623) possibly

highlighting not being listened to or their pain being minimised. Another participant mentioned being "left" for "about 8 hours" when in hospital (Renedo, 2020, p. 33).

Participants tended to speak about the conduct from nursing staff regarding pain. One participant said "she's like OK, I'm getting them, and then an hour later I still can't find her" (Renedo, 2020, p. 27).

2.5.4.2 Subtheme 2: Busy A&E

Participants described the busy environment and staff on A&E. There were clear differences in A&E compared to their routine specialist appointments with their regular doctors. Although participants acknowledged that A&E is busy and staff are helping others, they also highlighted how this affects them as "there might not be any chairs in A&E, you might not even get like a, a bed to be on until they call you out" (Renedo, 2020, p. 39). A participant felt deterred by going to hospital when unwell due to the atmosphere in A&E.

2.5.4.3 Subtheme 3: Feeling Undermined by Staff

In one study, participants felt undermined by staff which was demonstrated in staff interactions with behaviours or their body language. For instance, one participant thought the doctors "thought [he] was like faking" (Renedo, 2020, p. 28). Similarly, the perception of not being believed occurred across other subthemes whether in the school or work environment. One participant spoke about the idea of looking visibly unwell to be treated properly stating "you don't fit the textbook definition, so you shouldn't be here" (Renedo, 2020, p. 39). Participants often spoke about their perception of how others negatively perceived them. One participant said "the ignorant ones that don't understand and they think I'm a hypochondriac" (Atkin &

Ahmad, 2001, p. 623) highlighting the belief that others undermine their pain based on how they might present. One participant described an interaction with a HCP stating, "I don't like the way they talk to me sometimes" (Atkin & Ahmad, 2001, p. 623) highlighting an inconsistent response from HCPs. Participants described overhearing staff speaking about them negatively such as "they [ward nurses] say it [that you are a drug addict] amongst themselves and then you can hear it" (Renedo, 2020, p. 28).

Participants often reported being ignored by HCPs in A&E. Participants being ignored was expressed in staff not listening to patient needs regarding medication, injections or pain. For instance, a participant felt they were not being listened to during an injection, "so then I'll be trying to tell them where it is and they weren't really listening and they'll just be, like, moving my arm around a lot and it would hurt" (Renedo, 2020, p. 26). When a participant needed assistance, they felt they were being ignored: "you could hear it ringing in the nurses' station, but no nurse would, you know, come" (Renedo, 2020, p. 29). One participant described being ignored due to appearing calm which perhaps worked against them "I sort of got ignored [in the ward] when I was calm and everything was fine" (Renedo, 2020, p. 33).

2.5.4.4 Subtheme 4: Preference for Collaboration

Participants tended to speak about what they wanted from HCPs. For instance, the questions they wanted to be asked e.g. more personal questions about their feelings instead of the usual protocol. One participant said "they can't just do whatever, they have to know how I feel, about what I'm feeling" (Erskine, 2012, p. 27). Another participant said "as opposed to why are you feeling like this? How are

you feeling? What could possibly be wrong? Let's try and solve it" (Renedo, 2020, p. 39) highlighting their preference for more feelings-based questions.

2.5.5 THEME 5: IMPLICATIONS FOR THE FUTURE

Five studies included themes of future planning with SCD. This was considered important to individuals with SCD given their presentation. Planning consisted of academic, career and relationships.

Participants often spoke about their career aspirations and methodically choosing careers that did not involve exerting much energy or time. One participant said "I'm going to go to college to do an apprenticeship. I chose an apprenticeship instead of uni because of the fatigue. The apprenticeship will be a bit more manageable for me" (Poku et al., 2025, p. 12). Another participant said "we've to go by our energy limits, so we need to choose jobs within our energy limits to take care of our families in the future. That's why I want to be an architect. I have chosen architecture because of my energy level" (Poku & Pilnick, 2022, p. 1040). It appeared that participants might have compromised on their ideal career aspirations due to their SCD.

As well as careers, participants described the impact of SCD on future romantic relationships. One participant said, "maybe they won't like it if I had a crisis" (While & Mullen, 2004, p. 323) in terms of a future romantic partner. Another participant spoke about his future wife in terms of ensuring she does not have SCD potentially to avoid having children with SCD and for the sake of their relationship: "I can't marry a sickle cell woman when I grow up" (While & Mullen, 2004, p. 323).

2.5.6 THEME 6: EMOTIONAL IMPACT OF SCD

At least eight studies included themes of the emotional impact of SCD, whether on the young person or on others.

2.5.6.1 Subtheme 1: The toll on self and others

Participants spoke about the impact of SCD on themselves and their family members. When having a good day, a participant described their mood as "feeling emotionally satisfied and happy" (While & Mullen, 2004, p. 322). Participants often spoke about the impact of SCD on family members, which appeared to affect the participant emotionally. One participant believed his family were "worried about [him] and sometimes they don't have enough money for [his] treatment" (Atoui et al., 2015, p. 430). This participant highlighted the financial strain on his parents. Another participant said "my mum carries all the worry" (Erskine, 2012, p. 26). Being aware of how SCD affected their family made the participant feel sad and prompted them to want a good paying job to help their family. One participant described the positive impact of SCD and learning stating that "my granny and teachers are happy when they see me learning" (Poku et al,.2020, p. 1438), which in turn had a positive impact on the participant's mood.

2.5.6.2 Subtheme 2: Feeling like a burden

Participants demonstrated feeling guilty for having SCD. One participant said "sometimes I feel like I'm annoying them for like my sickle cell" (Renedo, 2020, p. 53) and another described feeling like a burden "and, um, I just feel like, like I'm annoying them" (Renedo, 2020, p. 53) when in pain and asking for help. Participants often labelled themselves as lazy perhaps to explain their tiredness and other people's perception of seeing or hearing about their tiredness. A participant said "I'll explain it and [. . .] I'll just make jokes about it saying, 'oh I'm, I'm tired, I'm, I'm

lazy', just blame it on that" (Renedo, 2020, p. 40). It appeared that participants also adopted the label of being lazy instead of accepting the importance of listening to their bodies and resting. One participant said "there's been days where I don't do anything and then I'll get used to not doing anything, so I'll get into the habit of being lazy" (Renedo, 2020, p. 51).

2.5.7 THEME 7: KNOWING WHAT WORKS FOR ME

Eleven studies included themes on knowing what works for me. Participants used different ways of managing their symptoms whether this included practical tips such as a healthy diet or pacing themselves to alternative coping mechanisms such as faith or religion.

2.5.7.1 Subtheme 1: Self-management

Participants spoke about various ways they manage their SCD and demonstrated an understanding of what works or does not work for them. One participant said "I have no energy to go out, so instead, I spend a lot of time at home watching television or playing video games, which I prefer anyway" (Atoui et al., 2015, p. 429). Although this participant lacked energy to go out, they knew other ways of stimulating themself while resting. Another participant mentioned "I just try and breathe" (Erskine, 2012, p. 22) to manage their SCD while another demonstrated knowing their limits: "I just make sure I don't walk too far" (Erskine, 2012, p. 22).

2.5.7.2 Subtheme 2: Religion

Participants spoke about the importance of religion in helping them manage SCD. One participant said how he prays saying "please help me get better. Help me get better" (Atkin & Ahmad, 2001, p. 621) highlighting the importance of faith in a

higher being to help them manage. Another participant described how their faith helps with pain "when I get the kreeza I have a great deal of suffering, but what do I do? I sit quietly, call upon God, recite prayers from the Quran, and say, Inshallah, tomorrow I will be better.'' (Atoui et al., p. 430). Another demonstrated his faith using a biblical verse and believing it for healing for his SCD ". . . by His stripes we are healed" (Clayton-Jones, 2016, p. 696).

2.5.7.3 Subtheme 3: Advocating

Participants described ways of advocating for themselves or others. One participant said "I started a [an advisory] board for kids with sickle cell . . . we are just kind of giving our input" (Clayton-Jones, 2016, p. 697). Another participant wanted to ensure that their voice was heard due to not wanting to "fall back into that time" in A&E (Renedo, 2020, p. 38).

2.5.7.4 Subtheme 4: Disclosure

Participants demonstrated mixed views regarding telling others about their SCD. While some participants thought it was important for others to know, some thought it was important for significant people in their lives to know. One participant said "my school and my friends have to know because I have crises often" (Erskine, 2012, p. 27). Another participant said "I feel better not telling my peers and teachers that I have sickle cell" (Forrester et al., 2015, p. 5) and one participant described not feeling comfortable "because I didn't really want to tell people about my condition, because I didn't feel comfortable about telling them" (Renedo, 2020, p. 46).

2.6 Discussion

This review systematically reviewed the literature to understand what is currently known about the lived experiences of young people with a SCD. This review identified 12 studies internationally, providing a comprehensive understanding

across countries. Young people with SCD experienced physical appearance-related challenges, school or work-related challenges, difficulties with interpersonal relationship dynamics and healthcare challenges. Future planning and coping with SCD were considered important given the emotional and physical impact of SCD.

Several participants reported negative experiences in A&E such as lengthy wait times and negative staff attitudes. These findings are consistent with the Sickle Cell Society (2025) that found "a lack of appropriate pain relief, inconsistent care, having to answer many questions while in pain and not feeling listened to or respected". The theme of neglect and mistrust in healthcare falls into the microsystem whereby the negative experience by healthcare professionals negatively affected young people. However, these experiences can also be explored by the exosystem, specifically the health policy makers where decisions made (or the lack of) may affect individual healthcare as reflected in staff attitudes and behaviour (Bronfenbrenner, 1979).

In line with the microsystem that highlights the impact of immediate support on young people, the review demonstrated the emotional and relational impact of SCD on young people and their families. Young people often spoke about their family members worrying and how it made them worry. While this depicts healthy family expressiveness which allows the young person to understand their feelings without shame or guilt (Mukherjee, 2026), this demonstrates the bidirectional relationship between the family and child. Young people described the conflict between wanting to prove themselves to peers in physical activities but knowing the detriment it would have on their bodies. In line with self-determination theory (Deci & Ryan, 2000), which highlights human motivation thrives when three basic needs are met, young people trying to prove themselves may pose as a threat to their basic needs

(autonomy, competence and relatedness). If they experienced a crisis, it would to less control over their health, reduced competence in what they can do and restrict any social interaction.

Young people considered friendships important; however, they were teased by peers for their physical appearance or when tired. While some were called lazy for not pushing themselves or joining in on activities, young people also self-identified as lazy when resting, which can be reframed as a coping mechanism to manage energy, re-charge and avoid pain crises. Perhaps being called lazy or the belief that others perceived them as lazy pressured them to think that they should always be doing something. Adopting the label 'lazy' could be viewed as a complex response to a chronic, debilitating and not always visible disorder that is internalised by societies stigma (Bulgin et al., 2019). Such views of laziness align with societal stigma associated with the idea that being productive equates to being more worthy and physical disorders being equal to a lack of drive (Bulgin et al., 2019).

Given the SCD related challenges, normality was a central theme among their experiences. Young people strived to develop an identity separate to their SCD and come across as "normal" like their peers. Research highlights that adolescents with SCD with reduced physical activity, social involvement and frequent school absence are at a higher risk of lower self-esteem (Nakabuye et al., 2026). During adolescence, which is marked by developing identity, likes and dislikes, SCD is likely to interfere with this process where young people are striving for a sense of belonging (Healthy Minds, 2026). Normality also demonstrates how young people navigate different roles through their interaction with various systems (e.g. peers, family, healthcare settings). This occurs at various levels such as micro or macro

(Bronfenbrenner, 1979) to fulfil roles or expectations outside of being a "patient with an illness".

Young people described additional roles such as being a student and future career roles. Academic and career decisions were planned in the context of SCD. Young people strategically chose less taxing academic courses and careers that did not involve high levels of energy, perhaps in line with identity formation (Erikson, 1950). Romantic relationships were considered important to young people but doubts persisted regarding being "wanted" for having SCD. Some of these concerns could have stemmed from the risk of having a child with SCD (Gallo et al., 2010) and the physical and psychological challenges on their significant other.

Studies highlighted the interpersonal challenges of having SCD but also the impact of tiredness and pain. Participants experienced chronic pain and tiredness which they attempted to manage by resting, taking pain relief, breathing and knowing one's limits e.g. not being too far away from a hospital or home. However, tiredness and pain affected young people's school attendance and grades, social interaction, work ethic, confidence and wellbeing. Both themes are consistent with adult research that highlight pain and tiredness as significant challenges of SCD (Kanter et al., 2023) and can be understood through the lens of the common-sense model of self-regulation which involves navigating the "threat" and creating action plans for it (Leventhal et al., 1980).

2.7 Strengths and limitations

This review used qualitative studies, which is ideal for exploring the experiences of young people with SCD as it captures rich and detailed accounts often missed in quantitative studies. Twelve studies were identified, which reflects a

reasonable number of studies across the globe. Including international studies broadened the scope beyond a western perspective, hence highlighting diverse views. The CASP tool ensured that studies demonstrated rigour, had low bias and a sound methodological process.

Limitations of this review included studies only written in English, potentially limiting the scope of other languages/perspectives. Only qualitative studies were used, which comes with their own limitations such as interpretation bias during data analysis. Future reviews could do a mixed methods approach to make the review more robust. All studies were extracted and screened by one researcher. However, the researcher discussed some of the studies with the research team to assess suitability for inclusion in the SLR. Limitations of one researcher completing the full screening for all studies includes researcher bias, or human error.

2.8 Rationale for the current study

The SLR explored what is currently known about the experiences of young people with SCD. The review highlighted challenges in A&E due to lengthy wait times, negative staff attitudes and slowness to respond to pain. Young people with SCD strived for normality even if it meant overexerting themselves under pressure to be perceived as normal, not lazy and to not let their peers down. However, this led to increased tiredness, pain or fatigue. Self-management included resting, breathing, knowing one's limits, drinking plenty of water and living a healthy lifestyle. Despite the challenges, family, friendships and others understanding the needs of those with SCD were considered important. Young people reported school related difficulties such as missing school, working out of school hours to catch up and there were mixed responses regarding support from school staff.

There is a vast amount of research that focuses on the child's experience of SCD through the lens of the parent, hence the voices of young people are often unheard. Decisions regarding care are often made on young people’s behalf by their parents or healthcare practitioners which highlights the need for this current research.

While research has explored how young people with SCD cope in different areas of their lives, there is a lack of research focusing solely on education in terms of difficulties experienced, support provided or reasonable adjustments and how young people respond to this. It is crucial to understand young people’s experience in school and how they are supported whether through peers, teachers or systems in place such as frequent breaks, rest areas or water breaks. Adolescents spend significant periods of time in education. For young people with SCD, it affects school attendance, academic achievement and can contribute to challenges with emotional wellbeing. These challenges can be predictive of later outcomes in life regarding job success, mental health and romantic relationships (Allen & Waterman, 2024). By focusing on education, this allowed me to understand individual experiences and help guide implications for education and how support can be improved. This may contribute to better outcomes in life for young people. Given the population of young people with SCD in England, it is important to better understand their experiences.

Qualitative research was used as it focuses on the “why” and “how” of human behaviour. It provides a deep understanding of meaning that cannot be captured by quantitative research. Qualitative research can uncover in depth information about complex phenomena, feelings and lived experiences in rich detail. It also gives a voice to participants by capturing their perspectives.

Research Aim and Question

To start to address the gap in the existing literature, the main research aim is:

Aim: To understand young people's experiences of being supported with sickle cell disorder within their educational setting.

Question: How do young people living with sickle cell disorder experience and make sense of their experiences within their educational setting?

CHAPTER THREE: METHODOLOGY

3.1 Design

This research is a qualitative research project that used Interpretative phenomenological analysis (IPA). Data collection and analysis was conducted from March 2026 to May 2026. Semi-structured interviews were conducted to explore the experiences of young people with SCD in education.

3.1.1 Interpretative Phenomenology Analysis (IPA)

IPA explores how people make sense of their major life experiences (Smith et al., 2021). IPA is rooted in phenomenology which is concerned with understanding how individuals experience the world and how we interpret those experiences. Hence, IPA focuses on the lived experiences of individuals and how they make sense of their experiences. This is in relation to their personal and social worlds, with a focus on personal meaning making. (Smith & Nizza, 2021). IPA explores the emotional experiences that tend to have a lasting impact on an individual's life.

3.1.2 The rationale

IPA is well suited to an inquiry exploring personal accounts of SCD as it allows participants to raise issues that are pertinent to them. IPA is a qualitative method that has been used to investigate how people give meaning to bodily states and health care decisions (Smith & Nizza, 2022). The approach engages with the perceptions and accounts of participants to capture characteristic features of the phenomena under investigation.

IPA is interpretative in that it gives recognition to variability in meanings and to the researcher's role in generating meaning from interview data. The aim of IPA is to deeply understand individual's experiences of SCD in education as opposed to generalising the findings. The hope is for IPA to allow young people to speak freely without reducing their responses to restrictive aims by the researcher.

IPA enables the in-depth exploration of the lived experiences from the perspectives of young people with SCD such as the psychological and physical impact of pain. Given the complexity of SCD, IPA provides a framework to understand how individuals give meaning to their lived experiences such as acceptance or resistance of SCD, how it affects their sense of identity or future plans in life e.g. career.

IPA can help to identify the gaps in young people's negative experiences and school's understanding and support between young people and schools, which could highlight the need for better provision. Highlighting individual experiences can better inform practice in school.

IPA was considered more favourable than other methods such as thematic analysis (TA), (Braun & Clarke, 2006) which is less individualised and focuses on identifying shared patterns across a data set. The theory behind IPA which is rooted within psychology and phenomenology compared to TA which is more generic was preferred. The double hermeneutics in IPA which involves the researcher making sense of the participant's meaning making of their world was preferred, due to fostering a deeper understanding of individual experiences and the richness within personal accounts.

3.1.3 Consultations

According to the NIHR, experts by experience (EBE) are individuals with lived, living and/or professional experience, knowledge and insight who directly contribute to and engage with research (NIHR, 2021). This research held two separate consultations (Appendix 3). One included an adult with SCD, a secondary school teacher and a paediatrician who works with young people with SCD. The second consultation included young people from Young Healthwatch, part of a participatory advisory group, and a £10 gift card was given for participation. Research highlights that involving EBE's in research have the potential for co-production in enhancing research, improving service delivery and influencing future research (Warmoth et al., 2025). EBE's provide a collaborative approach which can lead to improved outcomes and meaningful change (Warmoth et al., 2025). Their involvement can be recognised as pivotal and equal contributors to research.

In this research, the first consultation included discussions around the particulars of the study, recruitment and the feasibility of the interview questions. The EBE and consultant shared ethical queries relating to some aspects of the study that were removed and the specificity of the questions e.g. the need for questions to be clearer so participants were aware of what is expected of them. In line with their feedback, the interview schedule was adapted to be more specific to young people's experiences related to SCD. It was important to ensure that recruitment covered different areas in England as in the first consultation it was highlighted that there tends to be more focus on London. In the second consultation, young people gave their thoughts on the research poster (Appendix 4), interview schedule and process and dissemination. Young people thought the advert was too "wordy", less appealing for the target age range and lacking benefits for participants. They suggested participants are given the option to have soft pillows, drinks, snacks and the

interview is conversational and engaging. Dissemination included sharing the research with participants and SCD services.

3.2 Procedure

3.2.1 Participants

A purposive sampling method was used to identify potential participants for the research, as it supports IPA's premise of exploring how individual's make sense of their world (Noon, 2017), instead of random sampling which seeks generalisability. Five young people with SCD were recruited (2 through Cianna's Smile, a SCD Charity, and 3 via recommendation through a trainee clinical psychologist/researcher).

Table 5: Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Age 11-16 years old. *By focusing on this age range, I hoped to capture unique and variable experiences within one education setting e.g. secondary school.*	Participants under 11 years old or older than 16 years old.
Full-time secondary school education including mainstream or special schools. *To capture experiences unique to secondary school.*	Young people who are home schooled or in part-time education.
Sickle cell disorder*. Individuals with this diagnosis vary in terms of wellbeing, health and daily functioning compared to those with sickle cell trait may not experience difficulties.*	This research is excluding young people who are in crisis, have had a recent hospital admission or in need of a hospital admission as it would be unethical to have their participation, and their responses would not necessarily be a true reflection of their experiences but more so of how they are currently feeling health wise.
Young people must have access to a device with Microsoft Teams.	Young people who do not have access to Microsoft Teams.
Participants must be based in England.	Participants who do not live in England.

Participants lived in different parts of England – Luton, Milton Keynes, Kent, Suffolk and Ipswich. Four participants identified as Black British African and one identified as Black British Caribbean. See table 6 for further details. A sample size of 5 was sufficient as IPA focuses on the in-depth accounts of individual's lived experience (Smith et al., 2009).

Table 6: Participant demographics

Participant pseudonym	Ethnicity	Age	Gender	School year
Ebuka	Black British – Caribbean	12	M	Yr 8
Adaeze	Black British – African	15	F	Yr 10
Damilola	Black British – African	14	M	Yr 10
Shola	Black British – African	15	M	Yr 10
Chidinma	Black British – African	13	F	Yr 8

3.2.2 Recruitment

Research adverts for this study were shared via social media such as Instagram, SCD charities and SCD support services in England.

Most of participant's parents contacted the researcher to express an interest in the research. However, one young person contacted the researcher directly. She was encouraged to share her mum's email so contact could be made with her as she was under 16. All parents were emailed a parental information sheet (Appendix 5) consent form (Appendix 6), 11-15 year old information sheet (Appendix 7) and an

assent form (Appendix 8) for their child to sign and return. There were no young people age 16 although an information sheet (Appendix 9) and consent form (Appendix 10) were created ahead of recruitment. All participants were given a summary information sheet (Appendix 11). Participants were not restricted by a timeframe to read, sign and return the documents although the researcher contacted them if a few days had passed since receiving the documents. A demographic questionnaire was completed between the researcher and participant at the start of their interview (see Appendix 12). Participants were offered an opportunity to ask questions about the research by contacting the researcher via their email. An interview date and time was arranged with the parent. At the start of interviews, the researcher sought verbal consent from participants, to ensure that they were still happy to partake in the research.

All interviews were conducted online via MS Teams. Participants were required to be in a private room or space where they could do the interview. However, they were encouraged to have a parent with them if they wanted to or they were welcomed to do it alone. A parent/guardian was required to be at home for the interview duration where the researcher introduced themself to the parent and if there were any risks disclosed, the researcher could communicate this with their parent. No risks were communicated or observed during the interviews. At the start of interviews, the researcher sought to re-gain verbal consent from the parent to double check they were happy to go ahead.

3.2.3 Ethical considerations

Ethical approval was obtained from the University of Hertfordshire (protocol number: 0615 ST HSET 2026), (Appendix 13).

3.2.3.1 Consent and confidentiality

This research sought assent from all participants as they were under 16 hence not of consenting age and consent was sought from their parent. Although there is no official law for consent for research other than clinical trials, which prohibits children under 16 from giving consent (NHS Health Research Authority, 2024), this research followed this.

Participants were told that any personal identifiable information would be anonymised and the researcher spoke about the limits of confidentiality. For instance, if the researcher believed that they were at risk or someone else was at risk, then this information would need to be shared with the relevant people/services. Interviews were audio-video recorded using MS Teams and stored securely via the University OneDrive. Recordings were destroyed once the researcher completed their viva (September 2026).

3.2.3.2 Potential emotional distress

The researcher had access to supervision, peer supervision and their course tutor in the event of any distress experienced. Participants were encouraged to inform the researcher if they experienced any distress during their interviews however, they did not report any harm or distress. They were encouraged to share what they felt comfortable sharing and were given an option to take a break. All participants were given a debrief, which included contact details for services of support that they could access (Appendix 14).

3.3 Data collection

Semi-structured interviews developed in mind of IPA principles was employed to understand participant's needs. Interviews were held and audio-video recorded via MS Teams. The interview schedule included questions exploring young people's experiences of being supported with SCD in education. However, participants were invited to share what they wanted to share about their experiences, even if it did not relate to the questions. This fits with IPA which encourages participants to share their experiences in depth while letting them guide the conversation and share what feels important to them (Smith & Nizza, 2021). A summary of the interview schedule topics is in table 7 below, and the full schedule can be seen in Appendix 15.

At the start, participants were welcomed and asked how they were feeling. They were asked how they were coping throughout the interview to ensure that they were not in any pain, fatigue or experiencing any difficulties. Participants were reminded of their right to withdraw up until two weeks after the completion of their interviews.

Table 7: Interview schedule topics

No.	Topic area
1	Lived experience of SCD in education
2	Experiences of support
3	Relationships with staff and peers
4	Identity, independence and self-advocacy
5	Emotional impact
6	Looking back and looking forward

Interviews ranged from 25-60 minutes. Only one participant took a break for 5 minutes. All participants completed the interview and did not need to finish early. One interview was rescheduled as one participant was feeling unwell a day before the scheduled interview, hence it was rescheduled for two days later. All participants opted to do the interview alone however one participant had his mum near him. Although this research sought to hear the voices from young people, the parent who was close by provided two contributions – a schoolteacher's name and suggesting her son's favourite subject. After each interview, participants received a verbal debrief and were emailed an online copy which was sent to their parent's email. Each participant received a £20 gift card for their participation.

3.4 Data analysis

3.4.1 Transcribing the interviews

The interviews were transcribed using MS Teams. Following this the researcher reviewed the transcription for accuracy, making any changes to incorrect words transcribed.

3.4.2 Analysing the interviews

Table 8: The seven steps of IPA data analysis (Charlick, McKellar, Fielder, & Pincombe, 2015 adapted from Smith et al., 2009).

This table illustrates the stages involved in analysing data using IPA.

Stage	Analysis
1	Reading and re reading – *immersing* oneself in the original data.
2	Initial noting – free association and exploring *semantic* content (e.g. by writing notes in the margin).

3	Developing experiential statements – focus on chunks of transcript and *analysis of notes* made into themes.
4	Searching for connections across experiential statements – *abstracting and integrating* experiential statements.
5	Moving to the next case – trying to bracket previous themes and keep *open minded* to do justice to the individuality of each new case.
6	Looking for patterns across cases – find patterns of shared higher order qualities across cases, noting *idiosyncratic* instances.
7	Taking interpretations to deeper levels – deepening the analysis by utilising *metaphors and temporal referents*, and by importing *other theories* as a lens through which to view the analysis.

3.4.3 Stage 1: Reading and re-reading

Each transcript was read multiple times whilst watching the recording of the interview to gain familiarity with the data. This allowed the participant's voice to be the focus including their tone and changes in their expression. The process of bracketing during this phase allowed the researcher's thoughts to be put to one side in a reflective journal.

3.4.4 Stage 2: Initial codes

This process included making exploratory codes which consisted of descriptive (red), linguistic (blue) and conceptual (green) codes (see Appendix 16).

- Descriptive codes focused on relationships, memories or events that seemed to be important to the participant e.g. *"I try to go to school early to start work"*.

- Linguistic codes focused on the use of language such as words, terms or phrases, tone and non-verbal expressions. Examples of linguistic codes were *"love", "forced"* or repetition used to convey meaning.

- Conceptual codes focused on engaging with the text on a deeper meaning. Examples included "internalised stigma of having SCD" or *"desiring to be like peers despite having SCD".* This process involved understanding why participants were making sense of their experiences in the way they did.

3.4.5 Stage 3: Developing experiential statements

Themes were developed from the initial codes and captured participant's experiences. They reflected a synergistic process of description and interpretation (Smith et al., 2009). See Appendix 17.

3.4.6 Stage 4: Making connections across experiential statements

Once the experiential statements were developed, searching for connections between them, to identify the most important aspects of young people's narratives was the next step. A table was created where comparisons were made. Clusters were created e.g. Cluster A, Cluster B, Cluster C with theme labels summarising what was being said (Table 9, see Appendix 18. Each cluster had several subthemes which were supported by quotes to each theme and could be linked to the original transcript so the analysis could be traced to ensure good validity (Yardley, 2008).

3.4.7 Stage 5: Moving to the next case

The above procedure was repeated for each transcript one at a time to adhere to IPAs idiographic focus. Bracketing was helpful to reduce influence however I found myself being influenced through participant's narratives, the analysis and the SLR. Discussing this in supervision and highlighting it in the reflective journal was helpful to move away from this.

3.4.8 Stage 6: Cross case analysis

I looked across the experiential statements for each transcript to see whether there were connections (see Appendix 19). This involved re-naming themes at times to identify convergence and divergence within the narratives. Following this analysis, 4 group experiential themes and 12 subthemes (3 in each) were produced; see Appendix 20.

3.5 Reflexivity

Reflexivity in research refers to the continuous collaborative process whereby researchers self-consciously critique, appraise and evaluate how their subjectiveness and context influences the research process (Olmos-Vega et al., 2023). Reflexivity is important because qualitative research relies heavily on the information that participants provide. Given the subjectivity of qualitative research, it is important to be reflexive. In doing so, this reduces the risk of researcher bias within data collection, choice of the data collection method, the analysis of information and the reporting of information.

Double hermeneutics which is central to IPA allows the researcher to interpret the participant's interpretation of their world. This allows the researcher to

understand "how" participants interpret the meaning of their experiences and not just "what" they experience (Smith et al., 2009).

Prior to this study, I believed participants would present a negative experience of having SCD in education. Such beliefs were influenced by the SLR and the literature pertaining to SCD for young people and adults in education and healthcare. During interviews, when participants spoke about positive experiences I was taken aback but found myself digging for more. Once identified, I discussed this in supervision and recorded it in my reflective journal to be aware of this. Bracketing allowed me to set aside these biases and focus on what the participant was saying.

I was constantly aware of my position of power, being a trainee clinical psychologist/researcher as an "outsider" due to not having SCD. The interviews increased my awareness and uncomfortable feelings, but through supervision I realised the value in holding these positions and the contribution I could make to ensure participant's voices were heard. To "reduce" the power I tried to maintain a curious stance, allowing participants to guide me through their experiences instead of trying to control the narrative. Throughout the research, a reflective journal was kept to record observations and any emotions I felt during the interviews. During the interviews and analysis I felt a strong sense of emotion towards participant's experiences, and this made me realise how my emotions possibly influenced the interviews e.g. how I asked questions and what I was expecting to hear. By identifying and sharing this in supervision, it allowed me to separate my emotions from the interviews and further interpretation. A reflexive journal from the beginning of this research allowed me to document any concerns regarding recruitment, the sample and potential findings. By documenting these concerns, I was able to engage in bracketing to ensure the participants were at the centre of the analysis.

Given the current political context, regarding the rise of anti-immigration rhetoric and attacks, the propaganda from the Reform party perpetuated by the right-wing media, I was aware of how these contexts could influence the interviews or participant's attempts to make sense of their experiences. However, participants did not speak about any of these issues.

CHAPTER FOUR: RESULTS

This chapter provides an overview of the findings from the semi-structured interviews, including the data analysis and interpretation. The themes developed are discussed in depth, with quotes from the participant's interviews to illustrate each theme.

Four themes were generated following the data analysis. The four themes identified included:

1. Silently fighting an invisible illness others cannot see at school
2. Striving for a non-totalising view of living with SCD at school
3. Community, support and connection in education
4. Educators adapting care according to individual need

Table 10: Group experiential theme and sub themes

Group experiential themes			
Silently fighting an invisible illness others cannot see at school	Striving for a non-totalising view of living with SCD at school	Community, support and connection in education	Educators adapting care according to individual need
Sub themes			
Symptoms dismissed as an attempt of truancy by adults	Chasing normality despite physical limitations	Safety within friendships	Reasonable adjustments created for SCD symptoms
Lack of understanding from peers	Positive aspects of identity	Feeling left out	Support from teachers

Pain endurance	Advocating for SCD		The vital role of "medical" in physical pain management

4.1 Silently fighting an invisible illness others cannot see at school

All of the participants discussed the challenges they experienced when experiencing pain and how their concerns were treated or perceived by other people including their teachers and peers. This theme consistently came up amongst participants who felt that they were treated differently due to having an "invisible illness" and the incorrect assumptions that followed this.

4.1.1 Symptoms dismissed as an attempt of truancy by adults

This subtheme illustrates the participant's sense that their symptoms were dismissed as an act of truancy by adults. Ebuka described missing school due to feeling unwell and not being able to complete his homework, however on return, his teacher said "you have hands, you're able to do it". The inability to look past his physical being and understand what might have been going on for him was missed. This shared feeling of symptoms being dismissed and trying to manage her SCD symptoms was captured by Chidinma:

When I drink water and then I tell them I want to go to the toilet, they won't let me go. They'll just be like, oh, I think you want to go on your phone in the toilet.

While Chidinma described the challenge of trying to meet her body's needs and manage her SCD within the constraints of school, "they'll just be like" highlights

the dismissive response towards her and the incorrect assumptions made about coping with SCD. While the immediate response was to assume Chidinma wanted to use her phone, this appears to be ultimately driven by a lack of understanding of SCD and its management and perhaps the perception of adolescents wanting to truant in education.

Such attitudes extended internationally to Damilola who described challenges growing up in the Netherlands:

So sometimes when I get pain and like I'm studying or something, I get pain. They're like, it's too convenient. And they tell me that I'm pretending.

While Damilola highlighted how easily negative judgement is made, his repeated use of "I get pain" highlights the spontaneity and urgency of pain and the minimal control he has over it, that others fail to understand. The use of *"pretending"* possibly echoes the challenges young people with SCD experience in trying to prove their pain or have their voices heard.

Participants often struggled with feelings of sadness or frustration due to how they were treated and not being believed. Understandably such treatment could affect participant's self-concept and their help-seeking behaviours. Participants described difficult interactions with teachers; however, they also faced similar challenges from peers.

4.1.2. Lack of understanding from peers

Participants described assumptions made from their friends regarding their non-attendance, pain or abilities. Participants downplayed the severity of the

assumptions - they did not think their friends were being intentionally judgemental, or they tended to shrug off the comments in a bid to not cause a fuss. However, such comments highlighted a lack of consideration:

Like, if I'm not in, my friends will be like, oh, you were too lazy to come in, or why didn't you come in for a full week? Stop being lazy (Adaeze).

While she believed they were joking, which potentially highlights the lack of understanding from peers, she alluded to the comments as harmful. Language such as "…you were too lazy to come in" and "stop being lazy" illustrates the automatic stigmatised assumptions made about SCD and the attack on one's self-concept, which can have implications for internalised guilt, social isolation and a distorted self-concept. Damilola seemed to downplay the lack of understanding from peers:

You know, when I tell them that I'm having pains, you know, they laugh and then they now like, wish me well.

While this highlights an inappropriate response to the context, it appeared that Damilola found it humorous as he did not want to be treated as an exception, which could be understood from his challenges experienced in the Netherlands where he was doubted when in pain. Hence, laughing and wishing him well appears to be an improvement from his previous experiences. "You know" appears to indicate the frequency of pain or this kind of interaction with his peers. The contrast between laughing at pain and wishing him well could mean several things; an awkward response due to not knowing how to respond or it could be typical of adolescent

boys within Damilola's environment. Such contrast illustrates the challenges of having an invisible illness and the failure for others in education to see and respond appropriately to the illness.

Unlike the other participants, Shola described being "forced" to do things by peers:

Say for I'm getting forced like, say for other people running, they want me to run like, and sometimes they don't even, they don't know about the sickle cell, so, like, like, I can't run properly.

"Forced" highlights the lack of choice he has in decision making in strenuous activities at school. The use of repetition "so, like, like" possibly illustrates the difficulty in owning that he cannot run properly which possibly affects his self-concept. While this quote highlights a lack of understanding from peers, it also demonstrates their attempt at social inclusion.

In addition to the challenges experienced from peer's lack of understanding of SCD, two participants described direct influences of the power of the media on their peers' attitudes towards SCD in school. Adaeze and Damilola described how attitudes were influenced following the television series "Supacell":

…when Supacell came out, I felt like it just made everybody misunderstand so much more because people were like, oh, you have supercell (Adaeze).

I told them I have sickle cell and they're like, super cell. Do you have powers? What powers do you have? And it's like, ha ha ha (Damilola).

In school, peers already had a lack of understanding of SCD, however participants believed that Supacell increased the misunderstanding, which led to altered assumptions and perceptions of SCD. "Ha ha ha" indicates just going along with it, similarly to his peers laughing at his pain and wishing him well, however it illustrates the frustration in being misunderstood.

4.1.3 Pain endurance

Participants outlined different experiences of enduring pain at school:

> So during tests I kind of had to work two times as hard to finish at the same time as everyone else because during tests I do get quite tired or my hands will start cramping up and I'll be in pain, but I need to kind of like just push through it to finish with everyone else and do a good job on my test (Adaeze).

Adaeze illustrates the challenges of managing multiple demands in a system that does not cater for it. She highlights having to push through the pain in tests to avoid being left behind and to complete her work to a good standard. "Work two times as hard" illustrates the lengths she goes to and the physical and emotional demands it places on her that others do not experience. This ongoing cycle of pain is maintained by the inflexibility of the school system in reducing the demands. Her ability to endure the pain in tests speaks to her ability to achieve well academically and in her future career. Similarly, Damilola expressed his attempt to endure pain that starts in the middle of his lesson until he's unable to endure anymore.

Unlike Adaeze and Damilola who attempt to endure pain for various reasons, Shola depicts pain endurance as a mechanism of teacher's lack of understanding:

I don't like it again because I have to still like be in that pain whilst having to wait until the lesson finishes

His reference to "I don't like it again" emphasizes the impact of his pain being misunderstood and speaks to feeling as if he's being punished for having SCD. Prior to this Shola illustrated his frustration at teacher's not understanding his pain because they don't experience it. Responses from teachers such as "I can't do anything about it" demonstrates hopelessness and fails to acknowledge the physical illness – SCD, let alone manging the physical and psychological impact.

4.2 Striving for a non-totalising view of living with SCD at school

Participants tended to express ways in which having SCD made them feel different to their peers. Having a health condition their peers did not have, wanting to keep up with peers to avoid being perceived in a particular way or wanting to be known for their strengths or qualities instead of SCD were highlighted. Wanting to separate themselves from their SCD and focus on their qualities appeared to be related to their self-concept and to not feel held back by SCD.

4.2.1 Chasing normality despite physical limitations

Participants described wanting to be perceived as "normal" despite having SCD:

And I like to be athletic and I like to act like I don't have sickle cell (Ebuka).

While he had an interest in sports and was known to be one of the fastest, it is possible that he did not want his SCD to affect his reputation of being athletic despite the risks involved in pushing himself in vigorous activity and not listening to his body. Being an adolescent with SCD is a crucial developmental stage defined by the conflict between managing a chronic illness and the global adolescent drive for normality. Trying to navigate this appears to lead to an imbalance where normality is prioritised over health. The theme of chasing normality was seen across Adaeze and Damilola:

Sometimes I don't tell everything about my sickle cell because I could literally be in so much pain at school, but I will still act normal around my friends because I don't want them to like... see me when I'm at like my lowest and my weakest (Adaeze).

While Adaeze chases normality around her friends to protect her identity/self-concept, she acknowledges the power she holds in deciding what to share with others, however such power is reduced when pain starts. The use of language such as “lowest and weakest” illustrates the aspects of identity she does not want to be known for. This links to Adaeze’s earlier reports of being called lazy by peers, which perhaps she does not want to prove. Similarly, Damilola expressed normality in relation to the struggles of SCD:

I'm doing my best studying when I can at home, you know, but like, again, makes me feel like I'm not normal.

Despite the detriments of chasing normality could have on their health, wanting to be "normal" and not feeling "normal" often highlighted wanting to be known for other parts of their identity than the difficulties of SCD and highlighted challenges with their self-concept. Besides normality, participants spoke about positive aspects of their identity they were proud of.

4.2.2 Positive aspects of identity

Participants described the qualities they developed through the challenges of having SCD. They focused on the strengths which allowed them to get through their education despite the adversity they experienced. Participants expressed wanting to be known for their strengths as opposed to their SCD:

More perseverance than others because... Even on a day that I might be sick and unwell, I'll still come into school and I'll push through because I want to have my education. I want to be like known for my personality, my resilience, my intelligence. I don't want to be like remembered by my condition *(*Adaeze).

Comparing her ability to others allowed her to highlight the strengths she has gained in education as opposed to her limitations. Adaeze illustrates her value towards education and the skills that allow her to achieve well. "More perseverance than others" highlights a necessary trait to have to succeed. Reflecting on her strengths realigns her with aspects of her identity she is proud of but also highlights she is more than her condition. Chidinma described the relationship between her SCD and her mood:

I feel bad in some aspects and I feel good in some aspects because like it also helps you build your confidence over time and know that you're strong and smart.

Chidinma drew a contrast between SCD related difficulties and low mood and how through these difficulties it has contributed to her qualities. While there is much focus on SCD related difficulties, speaking about the bad first followed by the good attributes “confidence, strong and smart” could highlight wanting to focus on the good. These qualities could illustrate the ideal student traits from a teacher. Over time, Chidinma realised the qualities she has perhaps when there’s been a focus on the challenges or she had not yet realised her strengths. As well as the positive aspects of identity, participants discussed how they reach other people with SCD by using their position and platform to advocate for others.

4.2.3 Advocating for SCD

Using their voice to speak about SCD was considered important for participants. Adaeze’s journey to advocation seemed to stem from wanting to use her own experience to advocate for others:

I want to be able to talk about my personal experience with sickle cell and I want to be able to kind of be a voice for other people with sickle cell as well…So like a few months ago, I participated in the Jack Petchey Speak Out competition, and I did my speech on sickle cell, so I'm kind of becoming like more open to telling people about my sickle cell and just kind of educating people on it.

Adaeze illustrates her journey to speaking in front of an audience to advocate for other people with SCD. Adaeze strives to empower young people to have their voices heard, ensure equal access and challenge the stigma attached to SCD. Wanting to be "a voice" highlights the lack of voice young people with SCD have. The word "educating" highlights the lack of education others have about SCD. Similarly, Shola described how his SCD has led to wanting to speak more about it:

Is trying to make me like speak to other people about the sickle cell as well, like not even like my friends, probably the teachers as well.

His language "is trying to make me" illustrates how he's been pulled toward speaking about his SCD. Speaking to friends and teachers demonstrates his desire for SCD to be known across school. Similarly to advocating for SCD, community was considered important by participants, and the lack of community was evident.

4.3 Community, support and connection in education

The importance of community and the value it provided was important. All participants spoke about the richness of friendships, supportive teachers who understood them and "medical" (medical support teams). When participants felt isolated or left out this had an impact on their wellbeing.

4.3.1 Safety within friendships

Participants described friendships as valuable connections in their lives and tended to draw upon similarities between friends or shared interests or support:

And like, that's another reason why I really love my friends, both the ones online and in real life, because like, they don't treat me any differently (Damilola).

Damilola illustrates his friends seeing past his SCD and seeing him as an individual. His “real life” and “online” friends highlight the various social connections he has where he feels heard, valued and safe. Damilola further expressed how his friends support him:

But like with my friends, but like when they see that it's getting rough, you know, it's getting too much. That's when they start looking out for me, you know, because they don't want me to get hurt or sick.

This illustrates recognising individual behaviour and the impact on others to ensure safety and support in school. The use of language “they don’t want me to get hurt or sick” possibly demonstrates their awareness of SCD and how they can affect him. Similarly, Shola described his friends supporting him by taking him to the appropriate person when unwell, and Chidinma expressed how friends have positively added to her life:

When I actually came to the school, they helped me settle down and then they also like, they have been good friends and they also chat well with me as well…it was when my friends gave me their fidget toys to, like, hold onto, 'cause I wasn't so much, but I couldn't speak to anyone at that point.

These quotes highlight the multiple roles of friends such as a confidant, helper and emotional anchor, leading to validation, stability and security for participants.

4.3.2 Feeling left out

While participants spoke highly of friends, the absence of community due to school absence or not being able to join in on activities left participants feeling isolated. Participants described the challenges of not being part of the community and how it affected their sense of self:

> On days I'm sick and I can't come into school and my friends are just at school without me and they'll be telling me the stuff that happened while I wasn't there and I'll just feel kind of like bummed out because I wasn't there to experience it with them (Adaeze).

While friends are essential for emotional wellbeing, social development and belonging, Adaeze highlights how the separation from peers affects her wellbeing, leading to a sense of isolation. The contrast between being told “stuff” and being there to experience it for yourself highlights the conflict between having a community yet feeling isolated.

Similarly, Shola and Chidinma described the impact of feeling left out of peer-related activities:

> Like I feel tired or whatever, and they keep going on, don't want to like talk, whatever, they just keep playing, whatever…I don’t like it (Shola).

Shola recognises ways of coping when tired to avoid a crisis, however his desire for inclusive and flexible social connection is ignored. Although Damilola wanted to fully participate in sports with his peers, he had to listen to his body:

…I'm there, you know, I run out of breath, I feel sad and I have to go sit down and just to watch for either the rest of the lesson or half or half to rest to the lesson

While he understood the importance of putting his health before inclusion, this led to feelings of isolation. All participants described the challenges of missing out on lessons or tests due to being unwell. Although participants missed out on academic related activities, this also meant less time with friends and being a part of school-related activities.

The quotes highlight the importance of community and how difficult things can be when the community feels broken or distant. It demonstrates the value of having connectedness whether through friends or peers in a classroom. Although social connection was important for participants, listening to their body and understanding what they could or could not do was highlighted.

4.4 Educators adapting care according to individual need

Individualised care focuses on tailored care for young people with SCD that highlights their SCD, challenges, needs and puts support in place to meet their needs. The theme of adapting care according to individual need was expressed by all participants as valuable support. Adaptations were considered important factors in

managing their SCD in school to ensure they were giving their bodies what it needed.

4.4.1 Reasonable adjustments catered for SCD symptoms

All participants received reasonable adjustments in the form of passes. This consisted of toilet, break or lift passes which allowed participants to take themselves out of the classroom if they were in pain, needed to use the toilet or needed to avoid taking stairs. Such reasonable adjustments were valued by participants:

So because I have to drink a lot of water and fluid, I have a toilet pass, I have a medical pass. I have a lot of passes (Ebuka).

Ebuka's passes corresponded to his various needs. In doing so, this helps to prevent crises, manage pain and fatigue and improve overall wellbeing in education. The passes illustrate a shared understanding of Ebuka's needs. This was also expressed by Adaeze:

They've started to understand, they have my care plan in place, they've given me a lot of support, like I have a lift pass and a toilet pass and a uniform and medication pass.

The initial part of the quote highlights a gradual increase in understanding which was perhaps absent in school. Having a care plan provides protection and an individualised approach according to her needs. Shola and Chidinma also reported having access to toilet passes. The provision of passes ensures participants are

attending to their needs and have been developed for individual need. As well as reasonable adjustments, supportive teachers were highlighted by participants.

4.4.2 Support from teachers

Participants described how care and support was adapted according to individual need through teachers support. Participants spoke highly of the support received from teachers which made them feel heard and cared for:

But that's why most of my teachers, they'll put up like we have a Google classroom, so they'll put up work and revision on there for me for when I'm able to do it (Ebuka).

While this illustrates the flexibility of support and understanding of Ebuka’s needs due to when he’s “able to do it”, “most of [his] teachers” highlights a gap between teachers who are providing additional support with those who aren’t. The support also highlights that he is part of the class and not missing out. Adaeze illustrated joint up working between several staff members to meet her needs:

Like we went over my care plan with my sickle cell nurse and the school nurse and the SEND leader.

This illustrates a shared understanding where different specialisms are collaborating on her care needs to ensure her support in education is sensitive. Damilola described ongoing support from a specific teacher:

She, like, she was always looking out for me, you know, especially like usually I don't like wearing my blazer because it's either too hot or like it's uncomfortable. So usually when she's out and she sees me without my blazer, she tells me to put it on, like, because like she's worried that the cold will get to me, you know.

While this highlights the understanding of his needs to ensure he does not experience a crisis, Damilola mentions that wearing his blazer can make him feel hot or uncomfortable. Although his teacher has good intentions, telling him to put it on appears to dismiss his own experience. However, it appears that having a teacher who cares and shares her concerns is valued.

Chidinma highlighted the various ways she is supported by teachers:

The really good ones, um, they help when you like, um... sick or uncomfortable, they help tell you things, they ask you what you want and what you don't want. Or like when you get tired and you know you need to rest for a bit, they just lower the voice and things like that.

Chidinma receives this kind of support from “the really good ones” which shows a disparity of care across teachers. The support highlights the several ways support can be provided through having a conversation to understand their needs and adapting their communication or providing emotional support. This is vital in attending to their needs but ensuring that they are not alone. Support from teachers was considered important for participants, however all participants consistently discussed the reliability and support they received from “medical”.

4.4.3 The vital role of "medical" in physical pain management

Participants described the benefits of having "medical" and feeling understood. "Medical" referred to the staff who administered medication with a designated room for students to go to if unwell. "Medical" was described as someone who understood their needs without being questioned like their teachers:

> Probably if I need medication, like if I'm in pain, I go down to my medical room (Ebuka).

Ebuka depicts an immediate solution to his pain. Unlike participants explaining their needs to teachers or not receiving the support they need, access to medication appears to be a more straightforward process. Similarly, Adaeze, illustrates the benefits of "medical":

> I think if there was to be anyone, it would probably be the school nurse because she's probably the person who has the most knowledge about sickle cell. Now at this point, when I do go to get medication, she just understands straight away and if I do tell her that I'm not feeling well, that I need to go home, she does just send me home.

Adaeze describes a positive experience with "medical". Amongst the educators, she refers to "medical" as the most supportive due to having "most knowledge about sickle cell". This queries the level of knowledge amongst teachers but ultimately demonstrates feeling heard, valued and listened to. This experience of feeling heard was also shared by Damilola who expressed feeling pain and "medical"

supporting him and contacting the ambulance. Damilola shared that this experience allowed his pain to be managed instead of becoming a crisis. Participants demonstrated the challenges they experienced due to having an illness others cannot see in school. However, Shola expressed the opposite with "medical":

> One of the medical teachers, like they could tell straight away what was going on with me.

Shola depicts the reality of feeling heard by "medical" perhaps in a setting where his needs have not been typically or consistently met. His use of "tell straight away" highlights the immediacy of their response and possibly the urgency of his needs. This illustrates the possible familiarity, expertise and knowing what support is beneficial for his needs.

Summary of the findings

The findings revealed that participants experienced challenges with teachers in terms of not being believed when in pain or discomfort and negative assumptions made towards them. Although peers were considered important sources of support, negative assumptions were often made by friends which at times participants appeared to minimise. Participants wanted to be known for more than their SCD and instead their qualities and strengths. Participants described the importance of having people around them who supported them. This included supportive teachers, the medical support team and friends. However, when participants were absent from school due to ill health or when they couldn't join in on activities with others or tests, they felt isolated.

Participants described the benefits of having individualised support such as care plans or toilet passes that catered for their needs. Despite the challenges they experienced, they were able to celebrate the strengths they gained through having SCD.

The following section will review the findings by exploring how they support or contradict the literature and elaborate on the existing literature in the field.

CHAPTER FIVE: DISCUSSION

This chapter presents a summary of the analysis and the conclusions drawn from the findings. The study's findings in the context of relevant literature, connections to theoretical frameworks, clinical implications and recommendations for future research are presented.

The research question

The purpose of this research was to address the following research question: How do young people living with sickle cell disorder experience and make sense of their experiences within their educational setting?

5.1 Summary of findings

Participants described the ways in which their needs related to SCD were supported in their educational setting as demonstrated in four group experiential themes: silently fighting an invisible illness others cannot see at school, striving for a non-totalising view of living with SCD at school, community, support and connection in education and educators adapting care according to individual need. Participants expressed the ongoing daily challenges of having SCD while trying to navigate being a student such as attending lessons, completing homework, revising for exams and engaging in social interaction with peers. They were often faced with the dichotomy of wanting to achieve well in a system that can be restrictive. They described the challenges experienced with teachers and peers regarding their lack of understanding of SCD and how this influenced their decision-making which was heavily guided by misunderstanding and misconceptions of SCD.

5.1.1 Theme 1: Silently fighting an invisible illness others cannot see at school

Consistent with previous research exploring young people's experiences of education with SCD (Valenzuela et al., 2013), participants described the challenges of having an invisible illness where pain was misinterpreted as an attempt to avoid schoolwork. These findings are consistent with research highlighting that pain can be interpreted as psychological rather than physical in origin (Logan et al., 2007). Participants experienced challenges managing their SCD symptoms, however being in school coupled with the disregard of their symptoms added another layer of complexity. On multiple occasions, participants' needs were not only missed but negative assumptions were made. These assumptions appeared to be internalised by participants and seemed to question their trust in educators.

Such assumptions by teachers were echoed by peers. Stigmatised identities such as "you're lazy" resembles experiences of individuals in the healthcare system where patients are incorrectly labelled when requiring pain medication (Bulgin et al., 2019). Participant's pain met with laughter and being "forced" to engage in strenuous activities appeared to intensify the challenges participants experienced in education, leading to feelings of isolation (Bulgin et al., 2019), disempowerment and low self-concept. In an environment where their needs should be understood and catered to, this could have affected their feelings of safety.

These findings were echoed in the SLR where a participant was given detention for stopping during a PE lesson (Poku & Pilnick, 2022), not supported to catch up with work due to sickness (Moraes et al.,2019) and the adoption of a stigmatised label of lazy (Renedo, 2020). Participants' absence in education appears

to contrast with societal expectations of able-bodied individuals (Sapir & Benai, 2024), which could have added pressure for participants to conform to these expectations. In line with EST (Bronfenbrenner, 1979), the teacher-student relationship is most influential in a student's sense of belonging to their school (Allen at al., 2021) characterised by academic and emotional support (Ibrahim & El Sataari, 2020) and responding to individualised needs (Bouchard & Berg, 2017). Within the microsystem, negative assumptions represent the immediate social interactions that affect participants wellbeing, sense of belonging and sense of self. Although teacher's negative assumptions might not reflect prejudice, from an exosystem perspective, it could be explained through possible lack of training in awareness and supporting those with SCD (Prince at al., 2024). In line with the chronosystem, participants experience of their needs being dismissed over time may affect their trust in schoolteachers and willingness to tell others about their SCD.

5.1.2 Theme 2: Striving for a non-totalising view of living with SCD at school

Participants expressed ideas related to not wanting to be known for their SCD or wanting to minimise parts of their identity related to SCD. They highlighted the challenges of having SCD and not feeling normal. The idea of normality was consistent with the SLR where a participant said "…I am getting more normal as I get older" (Erskine, 2012, p24). A participant described masking chronic pain to avoid being perceived as weak, highlighting possible shame around SCD. Despite having a chronic condition, participants sought normality (Caress et al., 2018). SCD affected participants' identities as adolescents in line with the SLR which prevented them from doing "normal teenage things" (Poku et al., 2025, p. 11). Wanting to be "normal"

can be understood through the interaction between the participant and their macrosystem (Bronfenbrenner, 1979). SCD is a stigmatised diagnosis (Bulgin et al., 2018) and the public often lack understanding and form negative opinions about those with SCD (Royal & De Castro, 2011). Such stigmatisation can have harmful negative effects on well-being such as internalised stigma, anxiety, depression and social isolation (Ola et al., 2016). For individuals who talked to God or their friends or family about SCD pain, they had lower awareness of SCD stigma or being stereotyped and had better psychological adjustment (Derlega et al., 2014), highlighting the importance of positive support. However, all participants described positive relationships with their friends but not all of them spoke to their peers about their SCD pain. Strong peer relationships (microsystem) may act as a mitigating factor between negative assumptions held in broader society (macrosystem) that affects individuals.

Participants highlighted strengths they were proud of such as having "more perseverance than others" and wanting to be known for their "personality, resilience and intelligence" instead of their "condition". Other skills such as gaining "confidence over time" and realising strength and intelligence was expressed as proud attributes that could also be shared by peers. Erikson's psychosocial development (Erikson, 1950) highlights identity vs role confusion as a critical stage during adolescence and includes self-discovery where adolescents develop a clear sense of self by exploring their independence. Navigating this successfully leads to strong personal identity, increased confidence and healthier relationships. Identity involves relationships, experiences, values, beliefs and memories that contribute to an adolescent's subjective sense of self. However, for participants with SCD, managing pain and

fatigue may affect their journey to form stable identities, where they strive to focus on other aspects of their preferred identity.

For early adolescence (10-13 years old) young people are more conscious about their appearance and think they are being judged by their peers (Allen & Waterman, 2024). This fits with the younger adolescents in this research regarding normality but also extended to some of the older adolescents. Middle adolescence (14-17 years old) is marked by an interest in romantic relationships, with the exploration of sexual identity (Allen & Waterman, 2024). The effects of SCD such as delayed puberty, physical growth and health complications create tension in young people seeking a "normal" adolescent experience while trying to manage their SCD. The conflict between managing independence and health needs ultimately leads to the compromise of both depending on how much they can manage.

In a society that praises people for being independent, strong and persevering through adversity, it can create pressure which cannot be maintained in SCD and lead to difficulties with self-worth (Andoh, 2025). The idea of seeking normality and not wanting to be known for their SCD could also be explained by societal views of normality. While normality can be deemed a social construct which is fluid to time or place, the idea of normality to one participant was equated to not having a "health condition" hence resembling his peers/majority of people in the UK (Hutchinson & Robinson, 2026). The lived experiences of the participants could be made worse by stigma; lack of awareness and education they experience from those within their system. Participants identified the importance of having people around them who understood their needs which is discussed below.

5.1.3 Theme 3: Community, support and connection in education

When discussing support, participants often spoke about the value of friendships, supportive educators including "medical" and how support made them feel. In the absence of community due to missing school or not being heard, this had profound effects on their wellbeing, confidence and self-worth. Community came in many forms and is essential in supporting individuals with SCD (Desine et al., 2025) and previous research has found that adolescents with SCD are more prosocial (Noll et al., 2007). Similarly, to the findings the SLR highlighted benefits of friendships (Stegenga & Burks, 2013). Friends provided practical support to participants in the form of fidget toys, stability and emotive support. The importance of community, support and connection is echoed by EST (Bronfenbrenner, 1979) particularly in the microsystem where participants valued teachers' support, friendships and being part of lessons and tests. The exosystem could have a role whereby decisions made by education authorities on funding and resources allows schools to provide participants with the resources for SCD, although it was not something highlighted by participants.

In the absence of community, participants felt left out. This supports findings where participants who reported higher levels of loneliness also reported lower quality of life (Bediako & Wang, 2024). Given the challenges of loneliness (Bediako & Wang, 2024) and social isolation (Newcomb et al., 2025), increased social support is associated with lower psychological distress (Newcomb et al., 2025). In line with self-determination theory, when a student's basic psychological needs are met (e.g. autonomy, relatedness and connectedness) positive learning engagement occurs (Jeno et al., 2019). When an individual experiences frequent absence this can affect achieving their basic psychological needs. Their autonomy might be affected due to the unpredictable pain crises, which limits their control over their academia and

social experiences at school. Their competence could be affected due to missing out on learning hence leading to gaps in knowledge and falling behind. If making comparisons with peers, they may feel 'less than' academically and their ability to relate to peers may be affected due to missing out on social activities which might affect friendships.

Understanding adolescents' values can also help to make sense of the importance of community, support and connection. Values are developed during childhood and adolescence and consist of the quality of relationships, education and responsibility, shaped through supportive peer relationships (Smith et al., 2021). Adolescents value community as it provides emotional and physical security to explore and develop identity, form intimate relationships, enhance independence and provide closeness during stressors (Szwedo et al., 2017). In the absence of community, adolescents may experience identity formation difficulties, isolation and struggle with well-being (Brent et al., 2017).

5.1.4 Theme 4: Educators adapting care according to individual need

While participants highlighted the benefits of community and support, they also described positive experiences of individualised support. This included reasonable adjustments that recognised their health needs, such as opportunities to leave the classroom to use the toilet or have a break during pain episodes, and staff who understood their needs and familiarised themselves with their care plan.

These findings echo guidance for IHPs (Well at school, 2026) which was highlighted in the empirical study but not in the SLR. From a self-determination angle, participants experiences appeared to support their basic psychological needs.

Autonomy was enhanced when a participant was involved in the decision making about her healthcare and learning, which allowed her to communicate her needs. This gave her a better sense of control over her health and learning in school. Competence was promoted when a teacher provided catch up support via google classroom, which allowed a participant to continue to achieve while decreasing feelings associated with missing out. Relatedness seemed to be promoted through supportive teachers and "medical" who demonstrated kindness and compassion for participants. Feeling supported and heard allowed participants to remain connected to their peers and reduced feelings of separation. In line with the findings, research shows that individualised support may enhance participant's autonomy where they have more agency and motivation over their lives (Trouilloud et al., 2006). Higher levels of autonomy support, teacher's care, motivation and interest were reported among adolescents (Bieg et al, 2013).

In contrast, the findings of this current research were not supported by the SLR where individualised care was not mentioned by participants. It was not clear why it wasn't mentioned but maybe due to the challenges of having SCD outweighing the positives or a lack of individualised care or the interview questions used did not explore this. From literature searches, there does not appear to be much research exploring reasonable adjustments or individualised care.

Participants' positive experience of individualised care can also be understood through a social justice lens. Adolescents have limited opportunities for research involvement (Matsuda et al., 2016) and advocating for their needs in non-specialist settings (Renedo et al., 2019). While decisions are often made on behalf of young people by their parents, research demonstrates the differences in priorities between young people, parents and their carers (Conway, 2026). Barriers to basic care needs

includes delays in being given pain relief and lack of knowledge of SCD from healthcare professionals (Renedo et al., 2019). Meaningfully engaging young people in decision-making in education is important. Individualised care could also represent advocacy for participants where their voices are heard, their needs are considered and they are collaborators of their care as opposed to just recipients.

5.1.5 Further connection and contrast with the literature

Research highlights an intersection of race and SCD which involves the overlap of systemic racial inequalities and SCD-related implicit bias (The Kings Fund, 2025). Individuals with SCD often feel marginalised, and such frustrations stem from a lack of understanding and empathy within a system that does not always recognise their struggle (The Kings Fund, 2025). For visible health conditions, this tends to include immediate and continuous care, however for those with SCD, individuals are frequently proving their difficulties. The No One's Listening report (SCTAPPG, 2021) highlighted negative attitudes towards patients with SCD and evidence suggested that such attitudes were underpinned by racism. The findings in the report largely highlighted stigma and lack of prioritisation which led to SCD patients losing hope in the healthcare system. Furthermore, young people with SCD are at an increased risk of neurological complications such as silent cerebral infarction, stroke and cognitive difficulties (Lance et al., 2019). Research examining the aetiology of strokes found the most common cause of ischemic stroke was SCD (Earley et al., 1998). In addition, research demonstrates young people with SCD experience more cognitive difficulties such as executive function (Koelbel et al., 2023), impaired memory, processing speed and attention difficulties (Sahu et al., 2022).

With this in mind, neurological difficulties or race did not come up in participants' interviews. Potential reasons why race might not have been mentioned despite having been a feature in previous studies may be the assumption that the researcher understood based on their shared racial identity (Debrosse et al., 2025) or participants weren't explicitly asked about race hence did not mention it (Hamilton, 2008). Participants might have wanted to separate their "clinical identity" from their "racial identity" that is stereotyped (Anderson et al., 2023) and where they have less control over. Participants wanted to be known for more than SCD, hence discussing race could have minimised their efforts towards advocacy or in highlighting their positive attributes separate from their marginalised identities (Anderson et al., 2023).

Participants did not disclose any neuropsychological conditions or subsequent impact on their learning. While it is unknown why they did not speak about it, it is possible that they may not have these concerns. Hence, participants with such difficulties might have disclosed these in their interviews. Although participants described the challenges of having SCD, they demonstrated a preference for speaking about their strengths and reported not feeling "normal". Hence, discussing possible neuropsychological difficulties may have created more distance from their peers and been emotionally challenging for young people to disclose.

5.1.6 Implications for practice

Supporting the physical and psychological needs of young people with SCD is important to ensure they are given the same opportunities to succeed as those without SCD or medical conditions (Department for Education, 2015). Supporting young people in school with access to water and toilet breaks ensures they do not get dehydrated which can lead to pain. This is important as it may support them with

inclusion so they don't miss out on social activities with their peers and fall behind academically.

Understanding young people's needs means teachers and peers have a better understanding of young people's fatigue instead of misinterpreting their fatigue as "laziness" or attempts to avoid school. In doing so, this validates young people's experiences and ensures they do not feel othered for having SCD in school.

Young people with health conditions and their families experience four times more psychological distress than their peers without health conditions (Hysing et al., 2007). This can increase the risk of developing psychological difficulties which can affect their social, emotional and educational development and future occupation opportunities (Glazebrook et al., 2003; Lindblad et al., 2024). The impact of this will hugely depend on the environment they live in and the quality of care they receive from those around them (Law, Faulconbridge & Laffan, 2015). An emotionally healthy environment can prevent harm and reduce factors that lead to mental health difficulties (Law, Faulconbridge & Laffan, 2015). In contrast, additional stressors on parents such as financial issues, the disruption to their occupation due to attending to their child's needs and medical appointments can be an additional burden. Parental coping and wellbeing should be addressed as they can affect the child's ability to cope (Mercer et al., 2015).

Adolescence is an important stage for identity development, characterised by identity formation, increasing independence and peer relationships (Erikson, 1950). Given the challenges SCD poses, psychological support can help young people develop a wider sense of self so their SCD does not define their identity.

It is important for clinical psychologists to support schools with young people's physical and psychological needs. Clinical psychologists bring a unique

psychological perspective to health and mental health presentations, with the use of psychological models (Division of Clinical Psychology (DCP), 2010). Their perspective can be shared with educators when providing consultation and collaborating with IHPs (e.g mesosystem). Clinical psychologists can provide direct psychological interventions to young people (e.g. microsystem) or indirect work through workshops to staff and pupils to increase their understanding of SCD (e.g. mesosystem). The DCP highlights the importance of clinical psychologists providing an awareness of systemic issues within teams and in leading dynamic discussions. As "outsiders" of the education system, clinical psychologists input can be valuable for schools. Psychological services should aim to "improve the psychological competence of staff and provide governance for psychological interventions delivered by non-psychology staff. It should also educate and skill up front line staff across agencies and along the whole patient pathway, by providing training, consultation and psychoeducation" (Mercer, et al., 2015, p. 73). This can also apply to clinical psychologists' provisions in schools.

This research identified that young people viewed themselves as silently fighting an invisible illness that others cannot see at school. This highlights the importance of awareness:

- Clinical psychologists should be aware of the challenges experienced by young people due to possible interactions with teachers and peers and the implications this can have on their wellbeing, confidence and self-worth.
- Clinical psychologists can help increase awareness of fatigue, pain and attendance difficulties by liaising with education to provide consultation

on understanding and supporting the physical and psychological needs of young people.

- They may work with schools to discuss coping strategies such as relaxation or techniques to manage pain or distress.
- Clinical psychologists can collaboratively develop IHPs for students. Adolescents often obtain information online (Well at School, 2026) hence short videos explaining SCD in collaboration with medical staff, educators and young people with SCD may be helpful.
- Clinical psychologists should hold in mind potential difficulties of parents having a child with SCD and possible support needed.
- Teachers would benefit from receiving training on SCD to enhance their understanding and awareness of how SCD presents. Training should recognise the unpredictability of SCD and the impact on education and psychological functioning. Common misconceptions and negative assumptions should be addressed as well as language to avoid using. Teachers should be supported in recognising symptoms such as pain or fatigue and know how to appropriately respond e.g. giving young people options to have a break, access the toilet if necessary or sending them to "medical".

This research found that young people strived for a non-totalising view of living with SCD in school. This demonstrates the importance of supporting young people with their identity.

- Clinical psychologists may want to explore narrative therapy (White, 2007) with young people that encourages them to separate themselves

from their SCD through externalising e.g. giving their SCD a name or referring to it as "the sickle cell". This can allow them to tell their preferred stories through re-authoring or through spotting exceptions when their SCD has had less power over their lives.

- Clinical psychologists can explore Acceptance and Commitment therapy (ACT) (Hayes et al., 2006) which focuses on enhancing psychological flexibility, acceptance and mindfulness. Young people are encouraged to commit to their values alongside the challenges of having SCD. ACT acknowledges that suppressing negative feelings associated with controlling painful emotions can lead to more distress.
- Clinical psychologists may liaise with school counsellors and MHST in sharing the significance of ideas of narrative therapy and valued based support.

This research identified that young people valued community, support and connection and in the absence of this, it negatively affected their wellbeing. This highlights the importance of social inclusion for young people and support to catch up on missed lessons or assignments to reduce feelings of isolation.

- Mental Health Support Teams (MHST) in school: MHST can support young people to transition back to school following SCD related difficulties. They can be supported to have agency over their care in school and be participators of their care. MHST can be effective in supporting young people's wellbeing, reducing feelings associated with isolation and enhance connectedness.

- Counsellors: could provide students with a confidential space to discuss SCD related emotional difficulties.
- To minimise social disruption during absences, school can support young people to remain connected to peers through messages or shared online learning. Young people can be given a buddy who updates them about school events so they feel connected. Inclusive school trips or activities should be included such as adapting physical education where appropriate and ensuring medical support staff are available.

This research highlighted that young people benefitted from educators adapting care according to individual need using passes, IHPs and medical support staff. This highlights the significance of inclusive practice where the needs of young people are understood and listened to.

- IHPs should be reviewed annually to ensure they are accurately meeting individual need
- IHPs should be shared with non-permanent staff or a snapshot so they are aware of students with SCD and their adjustments.

5.1.7 Recommendations from participants

Participants had recommendations for the support they thought would make the biggest difference for students with SCD. It felt important to honour these recommendations, given the participant's lived experience, by sharing them here:

- Ebuka: Teachers should listen more and be more understanding.

- Adaeze: Teachers should receive SCD training to increase awareness and understand how to support students.
- Damilola: SCD should not be compared with other conditions and people should be more compassionate.
- Shola: All students with SCD should be told about support available to them.
- Chidinma: Students with SCD should have access to talk to someone or something to hold on to when in pain.

5.2 Strengths of the research

This research highlighted the lived experiences of young people in education based in England. This research adds to the previous small-scale studies based in England (Dyson et al., 2010). IPA allowed participants to speak in depth about their experiences and make sense of their lived experiences. It aimed to give them a voice over their experience which historically has been absent (Gov.uk, 2024). This research used a relatively geographically diverse sample as participants lived across the East, and South-Eastern England highlighting a range of voices according to region. Participants were between the ages of 12-15 years old which reflects a range of developmental stages and experiences within adolescence, and participants reflected on improved support as they got older. Recruitment covered participants through SCD charities and through another researcher who recommended this research to parents of young people who fit the criteria. Recruiting in different ways broadened the scope of the participants, perhaps reflecting regional differences in individual experiences.

5.3 Limitations of the research

Some of the participant’s parents were in the room during the interview. The presence of a parent during interviews may influence their responses. Participants might have been less willing to discuss sensitive issues or express views that differed from their parents', increasing the risk of social desirability bias. A further limitation of this research was the way questions were worded in the semi-structured interviews. Sometimes participants did not appear to understand the question based on the response they provided; hence this could have limited their responses. They sometimes limited their answers based on how they perceived the questions. The researcher discussed this in supervision, and they explored alternative ways of asking the question and using prompts to support participants.

5.4 Quality of the research

To assess the quality of this research, the CASP qualitative checklist (CASP, 2024) was used.

5.4.1 Validity of the results:

5.4.2 Clear statement of the research aims

This refers to whether there was a clear statement of the aim. The aim was discussed with the research team to ensure clarity for participants. The research aimed to explore young people’s experiences with SCD in education, given the challenges experienced in education and health (Dyson et al., 2010). This research was considered important due to the limited research on this topic area and the challenges young people face. The research aimed to contribute to literature on SCD and increase awareness.

5.4.3 Appropriateness of qualitative methodology

A qualitative stance was selected to illuminate the subjective experiences of participants. IPA is recommended when examining topics that are complex, ambiguous or emotionally laden (Smith & Osborn 2015). IPA was compared against other research methods however it was deemed most appropriate for young people with SCD.

5.4.4 Appropriateness of the research design to address aims

The research design was underpinned by the critical realist social constructionist epistemological stance, which is crucial as it bridges the gap between the biological reality of having SCD with the lived experiences such as stigma or support.

5.4.5 Appropriateness of recruitment relative to the aims

Five participants through purposive sampling were recruited via SCD support groups and word of mouth from a trainee clinical psychologist/researcher. Participants were recruited from different parts of England. Purposive sampling was appropriate for the study given the inclusion criteria to meet the research aim.

5.4.6 Data collection

The *data collection* phase involved a semi-structured interview (created by the researcher and shared with the research team) which allowed participants to draw on information that had not been asked in the questions and not feel restricted to yes or no responses. The use of prompts ensured support was provided for participants if stuck. Having interviews via MS Teams offered flexibility for participants and

allowed them to feel comfortable doing the interviews from the comfort of their own homes with access to water or snacks. MS Teams transcribed the interviews. Each participant offered new insights into their lived experiences hence data saturation was not a concern.

5.4.7 Relationship between the researcher and participants

Prior to conducting the research, a consultation with young people gave insight into building rapport with young people and reducing the power dynamic between a researcher and participant by how questions are asked and engaging with their stories. During interviews, introductory questions were asked about their day, friendships and school subjects to ease them into the interview. Positionality was set (See section 1.2) and a reflexive journal was kept for all assumptions made. See appendix 21.

5.4.8 The results:

5.4.8.1 Ethical issues

Participants were given information sheets, assent forms and debrief sheets and their parents were given parental information sheets and consent forms. A verbal debrief was also given to participants. Participant's wellbeing was checked throughout their interview and they were given the option to take a break. The exclusion of participants who had recently been hospitalised ensured that they weren't subjected to interviews. Data was only accessible to those in the research team and was secured on a password protected laptop on the UH one drive. All participant identifiable information was omitted from the results section. Ethical approval was granted from the University of Hertfordshire.

5.4.8.2 Sufficiency of data analysis rigour

The step-by-step process of IPA has been described in section 3.4. Triangulation was upheld; the academic supervisor looked over one transcript, and codes and themes were shared to ensure transparency of the analysis which led to reflexivity discussions.

5.4.8.3 Clear statement of findings

Chapter 4 highlights 4 group experiential themes and subthemes. The strengths and limitations of the research were explored – see sections 5.2, 5.3. All participants agreed to receive a summary of the results which can be found in Appendix 22.

5.4.8.4 Local application of the research:

Section 5.1.6 details the research implications.

5.5 Future research

To expand on this research, studies that include a sample of primary school age students and college/sixth form students would get a wider sense of lived experiences of SCD according to their stage of education. Typically, students in sixth form/college have less days in education, hence such flexibility could yield different results. A larger sample, and potentially a different qualitative approach such as narrative inquiry, could offer insights into more perspectives. A longitudinal design could explore how individuals with SCD experience changes across different developmental stages and how things develop over time. During the research

consultation with young people (see section 3.1.3), a consultant suggested obtaining parental and teacher's views to get different perspectives. While this has been conducted in previous research and was not in the scope of the current research, this could provide multi-perspective insights into this phenomenon.

Only one participant identified as Black British Caribbean; having more participants who shared this background could have yielded additional experiences or perceptions largely influenced by cultural values or practice. Participants did not speak about race or neurological difficulties; however future researchers could explore these areas further.

5.6 Significance

This research has hoped to give a voice to a marginalised population who have historical roots of structural and systemic inequalities in healthcare, research and education (The Kings Fund, 2025). This research aimed to gain an understanding of the lived experiences of young people with SCD, an area that is less explored and underrepresented due to lack of funding, research and treatment allocation (The Kings Fund, 2025). Hearing young people's voices in research ensures that their experiences are accurately reflected instead of relying on their parent's assumptions which might not always be accurate (Conway, 2026). Young people are best at understanding their lived experiences and their involvement might help to shape new interventions or initiatives. Including young people in research reaffirms that their voice is needed which can be empowering. This research is the first to explore young people's experiences of SCD in education in England using IPA. Hence, these findings contribute rich data to an area of limited research. Given

the findings of this research, it highlights avenues to be explored further such as greater awareness of SCD.

5.7 Final reflections

Prior to conducting this research, I had assumptions based on what participants would bring to their interviews. It was during the analysis when I realised my assumptions did not align with the findings. I assumed participants would speak about the intersection of SCD and race, drawing on the challenges of being a young black adolescent and how they're possibly misunderstood based on narratives that might have been shared by family members or their community. I anticipated that all participants would have only negative experiences of support in education largely based on the findings from my SLR and the literature I've come across. Hence, when a participant emphasized largely positive experiences in the UK, I found myself digging deeper in the hopes of a revelation of a negative experience that he perhaps forgot to mention. These assumptions were not accurate, and participants did not speak about race but solely focused on SCD in education.

Similarly to the SLR where race was mentioned, my identity as a black woman perhaps influenced my assumptions. The understanding I gained has revealed personal insights, including realising the extent to which I perceive race to be involved in all conversations. Reflecting on my personal experience of having sickle cell trait and the narratives shared from childhood – adulthood regarding reproduction, perhaps led to what I believed would be shared by participants. Reflexivity and supervision have allowed me to not become preoccupied with my own narrative.

During this research I felt struck by the challenges expressed by participants with SCD in their interviews. I often felt helpless hearing their stories while I sat in my position of privilege as an "outsider" who could continue with their life while they would continue to experience difficulties. I was often left with wanting to do more for participants and wondering whether I was doing enough. I was reminded that the research was doing something, which has been an enlightening experience. I have enjoyed getting to know participants and hear their stories. Bringing light to a phenomenon that has not received as much focus as other health conditions has been valuable. This research has left me with a greater sense of appreciation and a determination to engage in practice that enhances the support and awareness for young people with SCD. I feel motivated to disseminate this research to education, SCD charities, support groups and NHS organisations.

5.8 Conclusion

This research provided insight into the lived experiences of young people with SCD in education. IPA added to the development of unique and subjective accounts which could have been missed by more dominant methods such as quantitative research or less focused methodologies e.g. thematic analysis. IPA has facilitated the understanding of the complexities of SCD and the context of their challenges and strengths.

Participants shared the challenges they experienced, how it impacted them as well as the things that kept them going. The findings have implications for education, community and healthcare services. In addressing the difficulties experienced by participants, it is hoped that there will be greater awareness, care and sensitivity towards them, which will improve their experience.

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Appendices

Appendix 1: Prospero registration

NIHR | National Institute for Health and Care Research

PROSPERO

International prospective register of systematic reviews

What is currently known about the lived experiences of young people with a Sickle Cell Diagnosis (SCD)?

Nadine Oladokun, Megan Maidment

Citation

Nadine Oladokun, Megan Maidment. What is currently known about the lived experiences of young people with a Sickle Cell Diagnosis (SCD)?. PROSPERO 2025 CRD420251173582. Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD420251173582.

REVIEW TITLE AND BASIC DETAILS

Review title

What is currently known about the lived experiences of young people with a Sickle Cell Diagnosis (SCD)?

Condition or domain being studied

Sickle Cell Disease; Adolescence

Rationale for the review

This review is being conducted as part of a thesis in order to obtain a qualification for the Doctorate in Clinical Psychology. The empirical research attached to this SLR will explore how supported young people with SCD feel in education. While research has typically explored the experiences of adults with SCD, there is not as much research looking at young people's experiences. Whether in health care or education, decisions are often made for young people hence their voices are unheard. Hence, this research hopes to understand their experiences and contribute to current literature.

Review objectives

To understand the lived experiences of children of young people with SCD.

Keywords

Lived experiences; Sickle cell disease; Young people; Adolescents

Country

Young people's experiences of being supported with sickle cell disorder within their educational setting

England

ELIGIBILITY CRITERIA

Population

Included
Young people and adolescents

Sickle Cell diagnosis

Excluded
Adults 24+

No Sickle Cell diagnosis

Intervention(s) or exposure(s)

Included
No intervention or exposure included.

Excluded
No intervention or exposure included.

Comparator(s) or control(s)
This review does not have any comparators

Study design
Only nonrandomized study types will be included.

Included
Qualitative studies

Excluded
Quantitative

Mixed methods studies

Reviews

Studies not published in the English language

Context
Research exploring the experiences of individuals with a Sickle Cell Diagnosis has typically focused on adults. Where young people have been included, the voices of their parents have often been sought instead of directly asking the young people. In health

care, decisions are typically made on behalf of young people by their parents or health care professionals, minimising the voices and autonomy of young people. Research highlights the impact of Sickle Cell on health, education, navigating adolescence and identity among young people with Sickle Cell. Whilst there is research that explores young people with a Sickle Cell diagnosis's experiences whether through fatigue or pain or navigating their social contexts, it is important to understand what is currently known about the experiences of young people with a Sickle Cell diagnosis. Hence this review will aim to understand this and contribute to the current literature exploring this. This review hopes to bring awareness and insight into young people's daily experiences across the globe.

TIMELINE OF THE REVIEW

Date of first submission to PROSPERO
10 November 2025

Review timeline
Start date: 19 August 2025. End date: 29 December 2026.

Date of registration in PROSPERO
13 November 2025

AVAILABILITY OF FULL PROTOCOL

Availability of full protocol
A full protocol has been written and uploaded to PROSPERO. The protocol may be accessed through this link https://www.crd.york.ac.uk/PROSPEROFILES/df7975c63cf22f4b2d5bb9410007e2c3.pdf.

SEARCHING AND SCREENING

Search for unpublished studies
Only published studies will be sought.

Main sources that will be searched
The main databases to be searched are *PsycInfo* and *PubMed*.

Search language restrictions
The review will only include studies published in English.

Search date restrictions
There are no search date restrictions.

Other methods of identifying studies

Other studies will be identified by: *looking through all the articles that cite the papers included in the review ("snowballing" or forward citation searching)*, *reference list checking (backward citation searching)* and *searching trial or study registers*.

Link to search strategy

A full search strategy has been uploaded to PROSPERO. The PDF may be accessed through this link https://www.crd.york.ac.uk/PROSPEROFILES/d9f0fa8cffeb0dd1c766e3090cc0a8ce.pdf.

Selection process

Studies will be screened by one person (or a machine) and checked by at least one other person (or machine).

Other relevant information about searching and screening

Initial searches were conducted in May 2025 and the final searches were conducted in September 2025. This was to see whether there was any new literature since the initial searches were done. The search was conducted using Taylor and Francis, PubMed, Science Direct and Mag Online Library.

DATA COLLECTION PROCESS

Data extraction from published articles and reports

Data will be extracted by one person (or a machine) and checked by at least one other person (or machine).

Authors will not be contacted for further information.

Study risk of bias or quality assessment

Risk of bias will be assessed using:

The CASP tool will be used.

Data will be assessed by one person (or a machine) and checked by at least one other person (or machine).

Additional information will **not** be sought from study investigators if required information is unclear or unavailable in the study publications/reports.

Reporting bias assessment

The results section will highlight the findings in line with the CASP tool. Where there are missing results or queries regarding additional information that has not been highlighted in the findings, this will be highlighted in the discussion section.

Certainty assessment

The Critical Appraisal Skills Programme (CASP), (Burls, 1993). Qualitative Checklist will be used for all studies and will be checked and discussed by the research team. CASP provides a framework for critically appraising studies which allows for the assessment of the study's methodological rigour, relevance and validity. The framework presents 10 criteria that acts as markers for good quality appraisal of the methodological research. These include (1) Clear research aims, (2) Methodology (3) Design, (4) Recruitment, (5) Data collection, (6) Reflexivity, (7) Ethics, (8) Data analysis, (9) Findings, (10) Research value.

OUTCOMES TO BE ANALYSED

Main outcomes

This review will use qualitative research, hence outcomes cannot be measures. Instead this review will focus on themes.

Additional outcomes

There are no additional outcomes.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Thematic synthesis has been chosen for this review (Thomas & Harden, 2008). This consists of systematically identifying, analysing, and reporting patterns or themes. It involves three main stages: line-by-line coding of study findings, developing descriptive themes that are close to the original text, and generating analytical themes that offer a new interpretation beyond the primary studies. This method creates a transparent and comprehensive understanding by linking conclusions back to the original research. Thematic synthesis will occur via NVIVO 14 to support this analysis. Thematic synthesis was chosen due to its ability to move beyond themes and look at the meanings within the data.

CURRENT REVIEW STAGE

Stage of the review at this submission

Review stage	Started	Completed
Pilot work	✓	✓
Formal searching/study identification	✓	✓
Screening search results against inclusion criteria	✓	✓
Data extraction or receipt of IPD		
Risk of bias/quality assessment		
Data synthesis		

Young people's experiences of being supported with sickle cell disorder within their educational setting

Review status
The review is currently planned or ongoing.

Publication of review results
Results of the review will be published in English.

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members
Ms Nadine Oladokun (review guarantor). ORCID: 0009-0008-9208-6126. University of Hertfordshire. England.

No conflict of interest declared.

Dr Megan Maidment. University of Hertfordshire. England.

No conflict of interest declared.

Named contact
Dr Megan Maidment (m.maidment@herts.ac.uk). University of Hertfordshire. England.

Review affiliation
The University of Hertfordshire.

Funding source
Review has no specific/external funding but is supported by guarantor/review team (non-commercial) institutions.

Peer review
There has been no peer review of this planned review.

ADDITIONAL INFORMATION

Review conflict of interest
Declared individual interests are recorded under team member details.. No additional interests are recorded for this review.

Medical Subject Headings
Adolescent; Anemia, Sickle Cell; Child; Humans

SIMILAR REVIEWS

Check for similar records already in PROSPERO

PROSPERO identified a number of existing PROSPERO records that were similar to this one (last check made on 21 October 2025). These are shown below along with the reasons given by that the review team for the reviews being different and/or proceeding.

- Adolescents' and young people with sickle cell anaemia perspectives, views and experiences of sickle cell services [published 19 March 2018] [CRD42018091074]. The review was judged **not to be similar**
- What is the influence of internalised stigma on professional help seeking for young people with psychosis-like experiences? [published 17 September 2024] [CRD42024590344]. The review was judged **not to be similar**
- What are the lived experiences of attachment in relationships for people with intellectual disability? [published 22 December 2021] [CRD42021298478]. The review was judged **not to be similar**

PROSPERO version history

- Version 1.0, published 13 Nov 2025

Disclaimer

The content of this record displays the information provided by the review team. PROSPERO does not peer review registration records or endorse their content.

PROSPERO accepts and posts the information provided in good faith; responsibility for record content rests with the review team. The guarantor for this record has affirmed that the information provided is truthful and that they understand that deliberate provision of inaccurate information may be construed as scientific misconduct.

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Any enquiries about the record should be referred to the named review contact

Appendix 2: Table 11 Systematic review quality assessment (CASP)

Symbols: Low risk of bia Unc r High risk o bias

Paper	Research aim	Methodology	Design	Recruitment	Data collection	Reflexivity	Ethics	Data analysis	Findings	Research value
While & Mullen, (2004) Living with sickle cell disease: the perspective of young people	Clear aims set out	Semi - structured interviews to reduce bias. Consultation to assess questionnaire.	Questionnaires to reduce bias.	Opportunistic recruitment via a large caseload.	Data collected over a long period. Only one researcher seems to have collected the data.	No mention of reflexivity, which could influence the credibility of the interpretation of findings and the themes chosen. The researcher speaks about the challenges in collecting data from young people although this is not present regarding the methodology.	Informed consent was sought from participants.	Data analysis occurred through one researcher. It was not cross checked or shared with other researchers to gain alternative views or reduce possible bias. No mention of self-reflexivity.	Findings are clearly labelled, stating the themes with direct quotes from participants which fit the themes.	This research is a valuable contribution to the field of SCD. It highlights the need for young people's voices to be heard and provisions to be put in place regarding support for fatigue, social support and support when in pain or experie ng a crisis.
Atkin & Ahmad (2001). Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder	Clear research aim	Young people were interviewed twice – this allows the researcher to clarify information or assess change between the two time point, further strengthening	Research design appropriate for the aim.	The researcher does not state the sampling method from the health records.	The interview schedule was developed from reviewing literature on haemoglobinopathies, chronic illness and ethnicity and welfare, discussions with key informants, advice from an expert advisory committee and the researcher's previous work. This	No mention of reflexivity.	Considerations were made to participants who referred to be interviewed by someone of their own sex and ethnicity.	Rigorous analysis by several researchers.	Research findings clearly labelled and categorised into themes and supported by quotes.	This research is valuable in highlighting the difficulties experienced by individuals with SCD and sources of support and strength.

		the research. Young people were offered an interviewer of their own sex and ethnic background.			highlights the rigour of the data collection.					
Atoui et al., (2015). The daily experiences of adolescents in Lebanon with Sickle Cell Disease.	Clear aim stated.	This method captures individual meaning and experience of SCD which is appropriate. Rigorous screening to ensure participants were not in pain.	Appropriate design gaining valuable information from participants based on their experiences.	Participants recruited appropriately for the purpose of the sample.	Options for Arabic or English provided. Interview schedule developed by relevant literature and in consultation with a Clinical Psychologist and Paediatrician. The semi structured interviews followed the path of the respondents.	Lack of reflexivity highlighted in research.	Ethics followed and participants were given the choice to withdraw at any point without giving a reason.	Data analysis occurred by two researchers hence reducing bias.	Clear identification of findings with themes identified and quotes highlighted from participants in accordance with themes.	This research is a valuable contribution to research within SCD and highlights the need for research and provisions to not only focus on physical symptoms but to look at all areas of the lives of those with SCD.
Clayton-Jones et al., (2016). Spirituality and Religiosity in Ado	Research aim clearly stated.	Methodology is appropriate for the research and has rigour.	Design is suitable for the aims. Qualitative descriptive design allows researchers to stay close to what the participants are saying.	Recruitment occurred in an SCD centre hence is specific to the demographic of the research.	Demographic survey and two sets of interviews completed.	The main researcher reflected on personal and professional experiences and views about spirituality and religiosity before interviewing participants to explore assumptions and limit bias. A reflective diary included the researcher's thoughts,	Ethics followed.	Data was analysed by two researchers with an 80% agreement.	Findings are clearly stated with themes and quotes to support each theme.	This research highlights the importance of spirituality and religiosity in the participant's lives and in managing their SCD.

						hypotheses and reflections.				
Renedo et al., (2020). Understanding the healthcare experiences of people with Sickle Cell disorder transitioning to adult services: This Sickle Cell Life, a longitudinal qualitative study.	Clear aim stated.	Inductive analytical approach used.	The study was co produced with patients and carers.	Recruitment occurred via several sites.	Interviews – one off interviews and some participants completed repeat interviews.	Co produced study where they worked with non-medical, non-academic SCD experts throughout the study.	No mention of ethics.	Two approaches were combined hence strengthening the research's rigour.	The research highlights the journey and experiences of transitioning over a period of time which is reflected in multiple interviews.	This research highlights the importance of hearing the voices of those with SCD in shaping and improving healthcare outcomes.
Erskine, (2012). Adolescent boys with Sickle Cell Disease: A qualitative study	Aim clearly stated.	Appropriate methodology for the aim.	The overall design is appropriate and allows participants to make sense of their experiences.	Sampling was opportunistic, which reduces researcher bias.	Interviews were used and developed in consultation with a young person with SCD and two clinicians within the field.	The researcher consulted an expert by experience and clinicians within the field of SCD.	Ethics followed.	IPA is an appropriate data analysis to gain a sense of meaning making.	Results clearly highlight the findings from participants and split into themes with quotes.	The research adds to valuable research already available and highlights the male experience in particular.
Forrester et al., (2015). The lived experiences of adolescents with Sickle Cell Disease in Kingston, Jamaica.	Aim clearly stated.	Appropriate methodology for research aim.	Appropriate design and rigour.	Participants were recruited from a sickle cell unit.	Appropriate for the study.	Interviews were conducted by a graduate student to reduce bias. Consensus was gained on themes by the researcher and their supervisors.	Ethics adhered to.	Thematic analysis suitable for this inquiry.	The findings are clearly categorised and demonstrate valuable results.	This research adds value to the research of young people with SCD internationally.

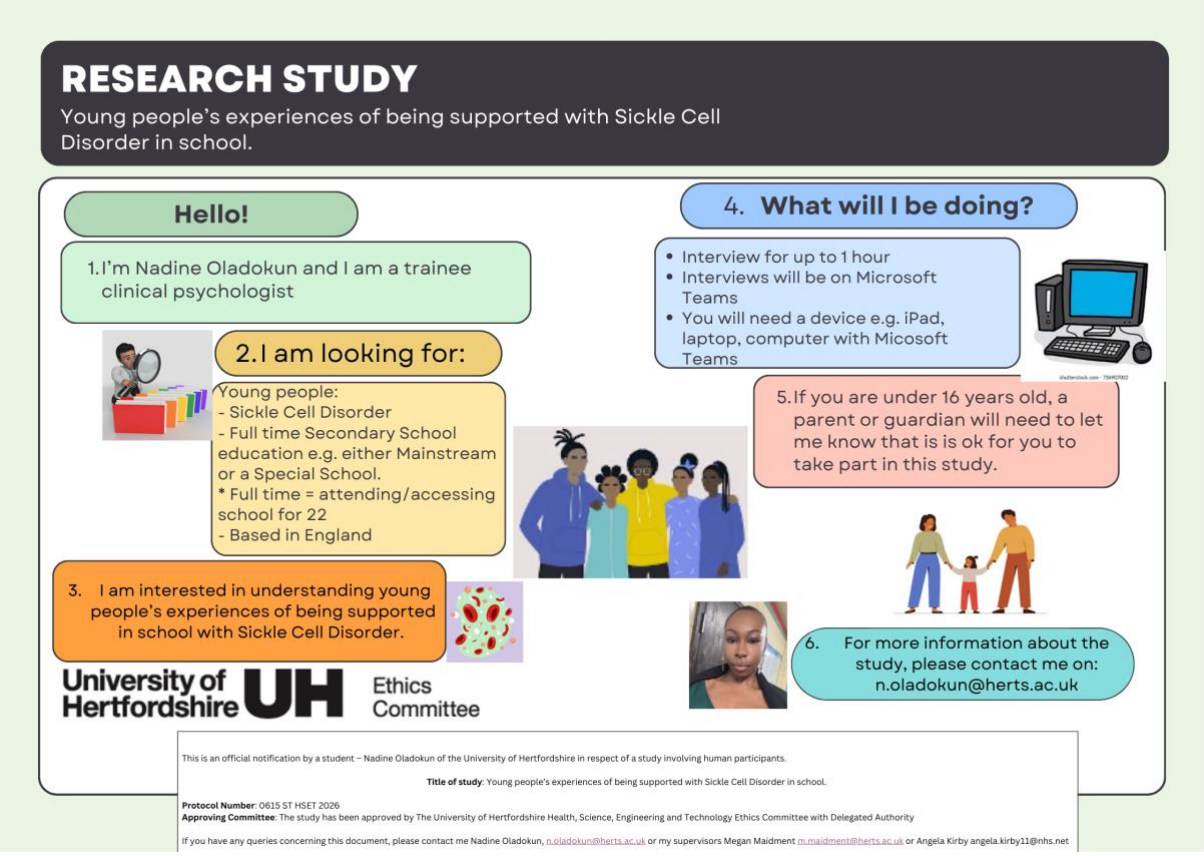
Moraes et al., (2020). The lived experiences of adolescent learners with Sickle Cell Disease.	Clear aim.	Appropriate methodology for the research.	Appropriate design allowing the exploration of meaning making and experiences.	Participants were recruited from the sickle cell unit – they were attendees.	Semi structured interviews were used however the researcher does not speak about whether the interviews were developed in consultation.	No mention of reflexivity.	No mention of ethics.	IPA – appropriate analysis for the research. Only one researcher analysed the findings.	Clear themes highlighted.	Findings are in line with other research highlighting the importance of such research.
Poku et al., (2025). "It's like going through life at a mediocre level: a qualitative study of the meaning and impact of fatigue in children and young people with Sickle Cell Disease	Aim is clearly identified.	Appropriate method.	Appropriate design, theory to support the aim.	Recruitment occurs via several clinics hence there is more representation.	Semi structured interviews and art based approaches and flexible approaches that complement each other and the latter is a creative method.	Increased credibility by having multiple coders and meetings held to discuss themes. Public and patient involvement reducing bias and opening research to more people.	Informed consent was given to all participants.	Credible data analysis by having multiple researchers involved in making sense of the findings.	Findings are clearly categorised into themes and supported by participants quotes.	Significant contribution to the field of SCD.
Poku et al., (2020). "Body as a machine": how adolescents with Sickle Cell Disease construct their fatigue experiences.	Relevant and appropriate.	Grounded theory used – appropriate methodology.	Appropriate research design.	Recruitment occurred across SCD clinics in Ghana hence more representative.	Multi method data collection – art-based designs which create flexibility. This can be empowering for participants and allow different insights into how they make sense of things.	Self-reflexivity present among the researcher.	Procedural and relational ethics present.	Analysis occurred via several researchers hence reducing bias and enhancing credibility.	Clear findings support the theory constructed. Quotes support the themes.	Significant contribution.
Poku & Pilnick (2022). Biographical accounts of the impact of fatigue in young people	Appropriate and clearly set out aim.	Theory gives power to young people which complements well with the research.	Appropriate design enhancing the autonomy of young people with SCD. Creative	Recruitment occurred across two SCD centres hence reaching a wider range of	Rich data collection methods that are empowering to participants and allows them to express themselves and take autonomy	Multiple coders and self-reflexivity mentioned.	Procedural ethics followed.	Adequate data analysis and reduced bias due to more than one researcher	Findings achieved the aim, clearly defines the themes and	Credible research and a significant contribution to the field.

with Sickle Cell Disease.			methods increasing the flexibility of the research and what the young people choose to bring a why.	participants. Sampling reduces bias.	over how they express themselves.			analysing the data.	quotes associated.	
Stegenga & Burks (2013). Using photovoice to explore the unique life perspectives of youth with Sickle Cell Disease: a pilot study.	Clear and achievable aim.	Appropriate methodology allowing participants to have more of a role in shaping the research.	Creative design giving power and autonomy to participants to express themselves in different ways.	Participants were recruited from a sickle cell clinic which is appropriate for the aim.	Creative and flexible data collection.	Two researchers involved in the data collection but no self-reflexivity was mentioned. Reflections were provided on the choice of method.	Ethics gained.	Data was analysed by two researchers hence reducing bias. Although both researchers has a lot of experience working within the field of SCD.	Findings are clear and support the research aim,	A significant contribution to research and healthcare.

Appendix 3: Table 12 Consultation feedback

Research reviewed	Consultants' comments	Changes made
Poster	• Too wordy • Not appealing • Lacking benefits to participants • Needs to be more related to SCD	• Words were reduced and the colour scheme was changed to pastel colours. • Due to space restrictions the benefits for participants was not highlighted besides wanting to hear from young people. However, in email correspondence, the benefits were shared.
Interview Schedule	• Interview questions were not specific to SCD • Interview needed to include a warm tone and be conversational	• Interview questions were reviewed and specific to SCD with prompts • Initial interview questions to set the scene e.g. favourite subjects, peers were introduced.
Interview practicalities	• To invite participants to feel comfortable by brining cushions, snacks or water.	• This was included in the information sheets.

Appendix 4: Research poster



Appendix 5: Parental information sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

PARENTAL INFORMATION SHEET

1 Title of study

Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

2 Introduction

Your child is being invited to take part in a research study. Before you and your child decide whether to do so, it is important that you both understand the study and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help for you and your child to make the decision. Please do take your time to decide whether or not your child wishes to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 What is the purpose of this study?

My name is Nadine Oladokun, and I am a third-year Trainee Clinical Psychologist at the University of Hertfordshire. I am exploring how young people living with sickle cell disorder experience and make sense of their experiences within their educational setting. Your child will be invited to a 1-hour interview to discuss what it's like having Sickle Cell and being in School. We hope to share study findings with charities and other services who support people with Sickle Cell to help young people receive better support. We can also share the study findings with your child's school if you/they wish (this would include overall themes and not specific information about your child).

4 Do I have to take part?

It is completely up to your child if they would like to take part or not. If they do decide to take part you and your child will be given this information sheet to keep and you will be asked to sign a consent form after 24 hours and complete a demographic questionnaire. Your child can complete the demographic questionnaire but if they need support you can help them. Agreeing to join the study does not mean that they have to complete it. They are free to leave the study (without giving a reason) at any stage up until I have started to analyse their data which will be two weeks after the end of their interview. A decision to leave (withdraw) or a decision not to take part at all, will not affect any treatment/care that your child may receive (should this be relevant). Any data collected from your child will be deleted immediately after they withdraw from the study

5 Are there any age or other restrictions that may prevent my child from participating?

Your child must be between the age of 11-16 to take part in this study. I am looking for 4-10 young people to be part of this study. Your child will not be able to take part in the study if they do not have Sickle Cell Disorder and do not live in England. We will not be able to talk to your child if they are currently having a Sickle Cell crisis or in need of hospitalisation or still recovering from a recent hospital admission. This is to ensure that we are not putting any undue stress on your child's health. They will not be able to take part in the study if they are not in full time secondary education e.g. mainstream or a special school. The interviews will be held online using Microsoft teams. Your child will need to have access to a device e.g. laptop, phone or computer with Microsoft teams and they will need to be in a private space e.g. in a room or space without other people. Young people can have an adult e.g yourself with them for their interview if they wish or they can do it independently. Young people will be asked again at the start of the interview if they would still like to take part and I will also ask you to provide verbal consent. You will need to be at home during the interview so I can introduce myself and if there are any concerns I can have a chat with you.

6 How long will my part in the study take?

If they decide to take part in this study, they will be involved in it for 1 hour for their interview. I will analyse their data for approximately 6 months.

7 What will happen to my child if I take part?

The first thing to happen will be to read the information sheet that you and your child will be given. You will also be asked to sign a consent form and your child will need to sign an assent form.

Your child will be invited to attend an interview to discuss their experience of having Sickle Cell and being in school. It will last for 1 hour and will be voice and video recorded. Interviews can take less than 1 hour, depending on how much information your child provides, however 1 hour will be provided in case your child needs more time.

I can schedule the interview at a time and date that suits you.

If your child would like you to stay while we talk that is fine, but I will be focusing on speaking to them as this study is about the views and experiences of young people. If your child would

prefer to speak with me on their own this is also okay, but I would ask that you are available nearby during the interview in case we need to speak with you about anything that comes up.

8 What are the possible disadvantages, risks, or side effects of taking part?

The main cost to your child will be the time needed to take part in this research.

I ask that your child only shares what they are comfortable to share during the interview, and that they do not have to answer all the questions asked if they do not want to. If they do find the interview difficult, they can stop taking part while it is ongoing; they will not be asked why they have left the study and there will be a debrief – sharing of information of what the study is about. This will be an opportunity to discuss anything they may have found difficult during the interview. The information in the debrief will not be recorded or included in the project findings.

If I notice visible signs of tiredness or distress or if your child reports they are tired, I will give them the option to take a break or reschedule the interview for when they are feeling better. I hope that your child will feel comfortable and have everything they need during their interview, so would suggest they bring anything that might help e.g. water and/or snacks.

The risk of distress for this research is low. However, if they feel distressed and feel they would like more support they will be given information for support. Please also note that there might be things out of their control that could lead to them having to stop taking part in the study (e.g. pain, fatigue/extreme tiredness or feeling unwell) if this happens, I will discuss this with your child.

9 What are the possible benefits of taking part?

We hope that your child will find this research interesting and fun and an opportunity to be a part of schools understanding young people with Sickle Cell and supporting them better. Your child will receive a £20 voucher as a thank you for their time.

10 How will we use information about your child?

We will need to use information that your child provides for this research project.

This information will include your child's:

- Name
- Your email address
- The type of school your child attends e.g. mainstream or special school
- Your child's year group
- Their age
- Ethnicity
- Where they live

This information will be used to do the research.

People who do not need to know who your child is will not be able to see their name or contact details. Your child's data will have a code number instead.

We will keep all information about your child safe and secure by:

- Giving your child's name and interview a code e.g. A
- Making private (anonymous) all personal details
- Not sharing information with anyone besides the research team
- Your child's information will be kept on a password protected laptop on the University of Hertfordshire One drive.
- When the research report is written, no personal information will be included, instead it will be themes.
- Your child's interview will be transcribed – this means typing up their interview word for word by myself. Personal information will be removed before transcription which will be on MS Teams. Only the research team will see your child's interviews.

If your child shares information that might mean they or someone else is in danger or at risk, then we might need to share this with yourself or other agencies. If your child shares concerns (e.g. any danger to themselves or other people) or raises a complaint about their experience in school, this information will be passed on to yourself.

Once the write up of the research has been completed the audio-video recordings will be deleted – September 2026. All data collected in this study, including participant and parental forms and recordings, will be stored in a secure, University of Hertfordshire supplied storage location until the end of the research/assessment process and then securely destroyed.

11 **Who has looked over the study?**

This study has been reviewed by: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The UH protocol number is 615 ST HSET 2026

12 **How will we use information about your child after the study ends?**

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study. I will ask your child if they would like to receive a copy of the results, which will be presented either in a leaflet or a summary.

The results of the research will be presented in a thesis (report) for the purpose of gaining a qualification in Clinical Psychology. The thesis will be held at the University of Hertfordshire Learning Resource Centre and will be accessible to all interested people. This research aims to be submitted to the Journal of Sickle Cell Disease.

Information from the study will only be made public in a private way – no young people involved will be identified.

13 **What are your choices about how your child's information is used?**

- Your child can stop being part of the study at any time up until two weeks after they have completed their interview (without giving a reason). If your child

decides to stop taking part they can contact me (see contact details below), following this your child's information will be securely destroyed by a member within the project's research team.
- Your child has the right to ask us to access, remove, change or delete data we hold about them for the purposes of the study. Your child can also object to our processing of their data. We might not always be able to do this if it means we cannot use your child's data to do the research. If so, we will tell your child why we cannot do this.

14 Where can you find out more about how your child's information is used?

You can find out more about how we use your child's information:

- By asking one of the research team via n.oladokun@herts.ac.uk, m.maidment@herts.ac.uk, or angela.kirby11@nhs.net

15 Audio-visual (video) material

If there is anything your child has said that includes identifiable information (for example, what school they go to, where they live, or their name) we will remove or change these details to protect your child's identity becoming known. I will make sure all possible care to ensure that your child cannot be identified by writing up our findings.

16 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, your child will be withdrawn from the study.

17 Who can I contact if I have any questions?

If you or your child would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email: n.oladokun@herts.ac.uk. Supervisors Dr Megan Maidment m.maidment@herts.ac.uk, Dr Angela Kirby angela.kirby11@nhs.net

Doctorate in Clinical Psychology
Wright Building
College Lane Campus
Hatfield
AL10 9AB

Although we hope it is not the case, if you or your child have any complaints or concerns about any aspect of the way they have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane

Young people's experiences of being supported with sickle cell disorder within their educational setting

Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to your child in taking part in this study.

Appendix 6: Parental consent form

University of Hertfordshire UH Ethics Committee

Parental Consent Form

Study title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting

PARENTAL CONSENT FORM (For children 11-15 years old)
UH protocol number: 615 ST HSET 2026

If you are happy for your child to take part, please complete and sign the consent form below

	Initials
1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my child's personal information on this form will be stored and for how long. I have been given details of my child's involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed and asked to renew my child's consent to participate in it.	
2 I have been assured that my child may withdraw from the study at any stage up until the researcher has started to analyse their data which will be two weeks after the end of their interview, without disadvantage to any support they may receive or giving a reason.	
3 In giving consent for my child to participate in this study, I understand that a audio (voice) and video recording will take place via Microsoft	

Teams and I have been informed of how/whether this recording will be transmitted/displayed.	
4 I have been given information about the potential risks or harm of my child taking part in this study. I have been told about the support available in the event of this happening, and I have been assured that all support would be provided at no cost to my child.	
5 I have been told how information relating to my child (data obtained in the course of the study, and data provided by my child about themselves) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used, including the possibility of anonymised data being deposited in a repository with open access (freely available). I have been told that my child's direct quotes in their interview will be included in the research report. All identifiable information will be replaced with pseudonyms or general descriptions, and quotes will be presented in a way that doesn't reveal participant identity.	
6 I understand that relevant sections of my child's data collected during the study, may be looked at by individuals from the research team where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my information.	

Signature of parent……..…Date……

Name of child……

Signature of researcher……Date……
…

Name of researcher *[in BLOCK CAPITALS please]*

……
…

One copy will be provided as a record for the study research team and one copy to the participant.

Appendix 7: Participant information sheet 11-15 year olds

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

PARTICIPANT INFORMATION SHEET – 11-15 year olds

1 **Title of study**

Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

2 **Introduction**

You are invited to take part in a research study. Before you decide it is important that you understand the study. Please read the information carefully and discuss it with your parent/guardian. Please do let us know if there is anything that is not clear. Please do take your time to decide whether or not you wish to take part. The University's guidelines, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **Why am I doing this study?**

My name is Nadine Oladokun, and I am a third-year student at the University of Hertfordshire. I am trying to understand young people with Sickle Cell. You will be invited to a 1 hour interview to talk about what it's like having Sickle cell and being in School. This interview can last under 1 hour depending on how much information you share.

I am looking for young people who might be part of local support groups or charities for young people with Sickle Cell or who might be on social media. If you want, you can share the study results with your school or if you're part of a local support group you can share it with them, as once the study is complete I will be happy to give you a leaflet or a summary about what I found out from young people.

4 **Do I have to take part?**

It is up to you if you would like to take part or not. If you want to take part you will be given this information sheet to keep and be asked to sign an assent form (a form to say you are happy to take part) after 48 hours. You will also be given a questionnaire that asks about your age, school and where you live and you can ask a parent or adult for support if you need help. You are free to leave the study at any stage up until I have started to study your interview information which will be two weeks after the end of your interview (without giving a reason). All you need to do is contact me using my email which is in section 16 of this document. This will not affect your support that you might receive in any service you attend.

5 What do I need to do the study?

You must be between the age of 11-16 to take part in this study and I am looking for 4-10 young people. You will not be able to take part in the study if you do not have Sickle Cell Disorder. We will not be able to talk to you if you are currently having a Sickle Cell crisis or need to go to hospital or still recovering from a recent hospital admission. This is to make sure that we are not putting any unnecessary stress on your health. You will not be able to take part in the study if you are not in full time secondary school and in England. The interviews will be held online using Microsoft teams, so you will need to have a device e.g. laptop, iPad or tablet. You will need to be in a private space e.g. in a room or space without other people. But if you want, you can have a parent or guardian with you for your interview. Before your interview a parent or guardian will need to be at home and I will introduce myself to them and ask them if they're happy for you to take part. You will also be asked again if you're happy to be in the study at the start of your interview. If you do not have a device with Microsoft teams, you will not be able to join the research.

6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for 1 hour for your interview and I will look at your interview for about 6 months.

7 What will happen to me if I take part?

The first thing to happen will be to read the information sheet that you will be given. You will be given a form to sign and your parent/guardian will need to sign a form too. You will also need to complete the questionnaire that asks about your school, age and where you live. If you turn 16 during the study, you will be asked again if you want to continue in the study and will need to sign a new form. If you do not want to take part, that is fine and you can let me know.

You will have a 1 hour interview to discuss your experience of having Sickle Cell and being in school. It will be voice and video recorded. Interviews can take less than 1 hour, depending on how much information you provide, however 1 hour will be provided in case you need more time.

8 What are the possible problems of taking part?

This study will need your time.

I ask that you only share what you are comfortable to share during the interview, and you do not have to answer all the questions asked if you do not want to. If you find the interview difficult, you can stop taking part while it is going on; you will not be asked why you have left the study and at the end I will speak to you about the study and why I am doing it. This will be a chance to discuss anything you may have found difficult during the interview and it will not be recorded or included in writing the report.

You might feel sad during the interview if you are speaking about things that have not been very nice, but the study will not make things feel difficult for you. If you feel very sad and would like more support you will be given information for places that can support you and I will have a conversation with your parent/guardian. There might be things out of your control such as pain or not feeling well that could lead to you having to stop taking part in the study; if this happens, I will discuss this with you and your parent/guardian.

If I notice that you might be tired or feeling unwell or if you say you are tired, I will ask you if you want to take a break or choose another date for the interview for when you are feeling better. I will also ask how you are feeling during the interview. I hope that you will feel comfortable and have everything you need, so would ask you bring anything that might help e.g. water and/or snacks.

9 What is good about taking part in this study?

We hope that you will find this study interesting and fun and an opportunity to be a part of something that will be helpful for schools. You will receive a £20 gift voucher to thank you for your time.

10 How will I use information about you?

We will need to use information that you give for this study.

This information will include your:

- Name
- Your parent/guardians email address if you don't have an email
- The type of school you are in e.g. mainstream or special school
- Your year group
- Age
- Ethnicity e.g. the country your parents are from
- Where you live

This information will be used to do the research.

People who do not need to know who you are will not be able to see your name or contact details. Your information will have a code number instead.

We will keep all information about you safe and secure by:

- Giving your name and interview a code e.g. A
- Making private all personal details
- Not sharing information with anyone besides the research team
- Your information will be kept on a password protected laptop on the University of Hertfordshire One drive – safe zone.
- Any direct quotes will be made private as they could be used in articles that people can see on the internet
- When the report is written, no personal information will be included, instead it will be themes.
- I will type up your interview word for word. Personal information will be removed before I type it up. Only the research team will see your interviews.

If you share information that might mean you or someone else is in danger then we might need to share this with your parent/guardian and other agencies. If you share concerns or raise a complaint about your experience in school, this information will be passed on to your parent/guardian.

Once the write up of the research has been completed the audio-video recordings and interview notes will be deleted – September 2026.

11 Who has looked over the study?

This study has been looked over by: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The protocol number is 615 ST HSET 2026.

12 Audio-visual (video) material

The interview will be written and recorded onto a written password protected word document. Any information that reveals who you are, or that gives any clues to who you are, will be removed.

You will not be named or identified if this research is made public.

13 What will happen to the data collected within this study?

At the end of the study, we will write a report in a way that no one can work out who took part in the study.

All data collected in this study, including participant forms, will be stored in a secure electronic storage on the University of Hertfordshire OneDrive, until the end of the research/assessment process and then securely destroyed.

14 Things that might affect other people

If during the study, any medical conditions or non-medical issues such as unlawful activity come to my attention that might or had put others at risk, the University may need to speak to other people, and if this does happen you will no longer be able to take part in the study.

15 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details, please get in touch with me, in writing, by email: n.oladokun@herts.ac.uk. Supervisors Dr Megan Maidment m.maidment@herts.ac.uk, Dr Angela Kirby angela.kirby11@nhs.net

Doctorate in Clinical Psychology
Innovation Centre
College Lane Campus
Hatfield
AL10 9AB

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and thinking about taking part in this study.

Appendix 8: Assent form

University of Hertfordshire UH Ethics Committee

ASSENT FORM FOR CHILDREN UNDER 16

Study title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting

UH protocol number: 615 ST HSET 2026

Child/Young Person (or if unable, parent/guardian/researcher to circle all they agree with:

- Has somebody else explained this study to you?
  Yes/No
- Do you understand what this study is about?
  Yes/No
- Have you asked all the questions you want?
  Yes/No
- Have you had your questions answered in a way you understand?
  Yes/No
- Do you understand it's OK to stop taking part up until your interview?
  Yes/No
- Are you happy to take part?
  Yes/No
- Are you happy for your voice and video to be recorded?
  Yes/No
- Are you happy to be on video?
  Yes/No

If <u>any</u> answers are "no" or you don't want to take part, that's OK! No one will be

cross with you.

I have been told that my parent/guardian has said it's okay (or have given permission) for me to take part, if I want to in this study. I know that I can stop at any time I want to and it will be okay if I want to stop.

If you do want to take part, please write your name below:

Your name _____

Date _____

OR

I have been told that my parent/guardian has given permission for me to participant, if I want to, in a study about young people's experiences of being supported with Sickle Cell Disorder within school.

Taking part in this study is up to me and I have been told that I may stop taking part in this study up until my interview has been studied/analysed by Nadine Oladokun which will be two weeks after my interview. If I choose not to be involved, it will not affect any support or care in any way.

Your name _____

Date _____

The researcher who explained this project to you needs to sign too:

Print Name _____

Sign _____

Date _____

Thank you!

Appendix 9: Participant information sheet (16 year olds)

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

PARTICIPANT INFORMATION SHEET

1 Title of study

Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

2 Introduction

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the study and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 What is the purpose of this study?

My name is Nadine Oladokun, and I am a third-year Trainee Clinical Psychologist at the University of Hertfordshire. I am exploring how young people living with sickle cell disorder experience and make sense of their experiences within their educational setting. You will be invited to a 1 hour interview to discuss what it's like having Sickle Cell and being in school.

I hope this study will offer us a better understanding on the experiences of young people's in school, and how this can be improved. We hope to share study findings with charities and other services who support people with Sickle Cell to help young people receive better support. We can also share the study findings with school if you wish (this would include overall themes and not specific information about yourself).

4 Do I have to take part?

It is completely up to you if you would like to take part or not. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form after 48 hours and complete a demographic questionnaire. You can complete the demographic questionnaire but if you need support you can ask an adult for help. Agreeing to join the study does not mean that you have to complete it. You are free to leave the study at any stage up until I have started to analyse your data which will be two weeks after the end of your interview (without giving a reason). A decision to leave (withdraw) or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant). Any data collected from you will be deleted immediately.

5 Are there any age or other restrictions that may prevent me from participating?

You must be between the age of 11-16 to take part in this study. I am looking for 4-10 young people to be part of this study. You will not be able to take part in the study if you do not have Sickle Cell Disorder and do not live in England. I will not be able to talk to you if you are currently having a Sickle Cell crisis or in need of hospitalisation or still recovering from a recent hospital admission. This is to ensure that I am not putting any unnecessary stress on your health. You will not be able to take part in the study if you are not in full time secondary education e.g. mainstream or a special school. The interviews will be held online using Microsoft teams, so you will need to have access to a device e.g. laptop, phone or computer with Microsoft teams and you will need to be in a private space e.g. in a room or space without other people. You can have an adult e.g. parent or guardian with you for your interview if you would like to or you can do it independently. A parent/guardian will need to be at home during your interview, and I will introduce myself to them before we start. If there are any concerns I will have a chat with them. You will be asked to provide verbal consent at the start of your interview. If you do not have a device with Microsoft teams, you will not be able to join the research.

6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for 1 hour for your interview. I will study/analyse your interview for approximately 6 months.

7 What will happen to me if I take part?

The first thing to happen will be to read the information sheet that you will be given. You will also be asked to sign a consent form, followed by completing a demographic questionnaire.

You will be invited to attend an interview to discuss your experience of having Sickle Cell and being in school. It will last for 1 hour and will be voice and video recorded. Interviews can take less than 1 hour, depending on how much information you provide, however 1 hour will be provided in case you need more time.

I can schedule the interview at a time and date that suits you.

8 What are the possible disadvantages, risks, or side effects of taking part?

The main cost to you will be the time needed to take part in this research.

I ask that you only share what you are comfortable to share during the interview, and that you do not have to answer all the questions asked if you do not want to. If you do find the interview difficult, you can stop taking part while it is ongoing; you will not be asked why you have left the study and there will be a debrief – sharing of information of what the study is about. This will be an opportunity to discuss anything you may have found difficult during the interview. The information in the debrief will not be recorded or included in the project findings.

If I notice visible signs of tiredness or distress or if you report you are tired, I will give you the option to take a break or reschedule the interview for when you are feeling better. I will also ask how you are feeling during the interview. I hope that you will feel comfortable and have everything you need during your interview, so would suggest you bring anything that might help e.g. water and/or snacks.

The risk of feeling down/very sad for this research is low. However, if you feel very sad and feel you would like more support you will be given information for support. Please also note that there might be things out of your control that could lead to you having to stop taking part in the study (e.g. pain, fatigue/extreme tiredness or feeling unwell); if this happens, I will discuss this with you.

9 What are the possible benefits of taking part?

We hope that you will find this research interesting and fun and an opportunity to be a part of schools understanding young people with Sickle Cell and supporting them better. You will receive a £20 voucher as a thank you for your time.

10 How will we use information about you?

We will need to use information that you provide for this research project.

This information will include your:

- Name
- Email address or your parent/guardians if you don't have an email
- The type of school you are in e.g. mainstream or special school
- Your year group
- Age
- Ethnicity
- Where you live

This information will be used to do the research.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure by:

- Giving your name and interview a code e.g. A
- Making private (anonymous) all personal details
- Not sharing information with anyone besides the research team
- Your information will be kept on a password protected laptop on the University of Hertfordshire One drive.
- When the research report is written, no personal information will be included, instead it will be themes.
- Your interview will be transcribed – this means typing up your interview word for word by myself. Personal information will be removed before transcription which will be on MS Teams. Only the research team will see your interviews.

If you share information that might mean you or someone else is in danger or at risk then I might need to share this with your parent/guardian and other agencies. If you share concerns or raise a complaint about your experience in school, this information will be passed on to your parent/guardian.

Once the write up of the research has been completed the audio-video recordings will be deleted – September 2026. All data collected in this study, including participant forms and recordings, will be stored in a secure electronic storage on the University of Hertfordshire OneDrive until the end of the research/assessment process and then securely destroyed.

11 **Who has looked over this study?**

This study has been reviewed by: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The UH protocol number is 'TBC'

12 **How will we use information about you after the study ends?**

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. I will ask you if you would like to receive a copy of the results, which will be presented either in a leaflet or a summary.

The results of the research will be presented in a thesis (report) for the purpose of gaining a qualification in Clinical Psychology. The thesis will be held at the University of Hertfordshire Learning Resource Centre and will be accessible to all interested people via the University of Hertfordshire – Library Search database. This research aims to be submitted to the Journal of Sickle Cell Disease.

Information from the study will only be made public in a private way – no young people involved will be identified.

13 **What are your choices about how your information is used?**

- You can stop being part of the study at any time up until two weeks after you have completed your interview (without giving a reason). If you decide to stop taking part you can contact the me (see contact details below), following this your information will be securely destroyed by a member within the project's research team.

- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

14 Where can you find out more about how your information is used?

You can find out more about how we use your information:

- By asking one of the research team via n.oladokun@herts.ac.uk, m.maidment@herts.ac.uk, or angela.kirby11@nhs.net

15 Audio-visual (video) material

If there is anything you have said that includes identifiable information (for example, what school you go to, where you live, or your name) we will remove or change these details to protect your identity becoming known. I will make sure all possible care to ensure that you cannot be identified by writing up our findings.

16 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become obvious that might or had put others at risk, the University may refer the matter to the appropriate people and, under such circumstances, you will be withdrawn from the study.

17 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email: n.oladokun@herts.ac.uk. Supervisors Dr Megan Maidment m.maidment@herts.ac.uk, Dr Angela Kirby angela.kirby11@nhs.net

Doctorate in Clinical Psychology
Innovation Centre
College Lane Campus
Hatfield
Hertfordshire
AL10 9AB

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield

Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix 10: Participant consent form

University of Hertfordshire UH Ethics Committee

Participant Consent Form for 16 year olds

Study title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting

CONSENT FORM

I, *[please give your name here*, *in BLOCK CAPITALS]* agree to take part in the study

……

……..…

(UH Protocol number ……)

	Initials
1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) including all of the information of the study, the names and contact details of key people e.g. researcher and the research team, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve contacting you again to take part. I have also been told how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that if there are any big changes to any part of the study I will be told, and asked to sign a new consent form if I would like to take part.	
2 I have been told that I may stop taking part from the study at any time up until the researcher has started to study my data which will be two	

weeks after the end of my interview, without giving a reason and without this affecting any support I receive.	
3 In giving my consent to participate in this study, I understand that audio (voice) and video recording will take place on Microsoft Teams and I have been told how/whether this recording will be used.	
4 I have been given information about the potential risks of taking part in this study. I have been told about the support available if I need to speak to someone, and I have been told that all support would be provided at no cost to myself.	
5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used, including the possibility of anonymised data being kept with open access (freely available). I have been told that quotes from my interview will be included in the study's report. All identifiable information will be replaced with pseudonyms (e.g. a made up name or a number) or general descriptions, and quotes will be presented in a way that doesn't reveal my identity.	
6 I understand that relevant sections of my data collected during the study, may be looked at by individuals from the research team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my information	

Signature of participant……..…Date……

Signature of researcher……Date……

Name of researcher *[in BLOCK CAPITALS please]*

……
…

One copy will be provided as a record for the study research team and one copy to the participant.

Appendix 11: Summary participant information sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

SUMMARY PARTICIPANT INFORMATION SHEET

Title of study

Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

My name is Nadine Oladokun, and I am a third-year Trainee Clinical Psychologist at the University of Hertfordshire. I am trying to understand the experiences of young people with Sickle Cell in education. You will be invited to a 1 hour interview to discuss what it's like having Sickle Cell and being in School. I am looking for 4-10 young people between the ages of 11-16 in full time secondary school education who have a diagnosis of Sickle Cell Disorder and have access to Microsoft Teams. Interviews will offered online and you will need to have a parent or guardian at home where I will introduce myself to them before the study. You can also have a parent with you for your whole interview if you want.

You are free to leave the study at any time up until I have started to study your data which will be two weeks after the end of your interview, without giving a reason. You can contact me using my email which can be found on the main participant information sheet. You only need to discuss what feels comfortable. Your interview will be audio-video recorded and this will be deleted once the study has finished – September 2026.

In this study we will use information that you provide. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

We will make sure no-one can work out who you are from the reports we write.

The information pack tells you more about this.

Appendix 12: Demographic questionnaire

University of Hertfordshire UH

Participant demographic Form

Study title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

ABOUT YOU

1. Are you?

   Male ☐ Female ☐ Other ☐

2. What is your age?

   ☐

3. Are you in a mainstream or specialist school?

   Note: A mainstream school is where you learn alongside students of all abilities. A specialist school is for young people with special educational needs and disabilities offering tailored support and resources.

   Mainstream ☐ Specialist ☐

4. What year of school are you in?

   ☐

5. To which of the following groups do you belong (please tick all that apply)?

   Black British – African ☐

   Black British – Caribbean ☐

   Any other Black / African / Caribbean background, please describe

   _____

   Asian/Asian British – Indian ☐

   Pakistani ☐

Bangladeshi ☐

Chinese ☐

Any other Asian background, please describe
_____

Mixed/Multiple ethnic group ☐

White and Black Caribbean ☐

White and Black African ☐

White and Black Asian ☐

Any other mixed/multiple ethnic background, please describe_____

Other ethnic group, please describe

_____

6. Where do you currently live?
    - Greater London
    - South East
    - South West
    - West Midlands
    - North West
    - North East
    - Yorkshire and the Humber
    - East Midlands
    - East of England
    - Other (Please state)

You can ask an adult for support if you are having any problems answering the questions.

Young people’s experiences of being supported with sickle cell disorder within their educational setting

Thank you for completing this survey. No information you have provided will be used to personally identify you. Please return the completed form to n.oladokun@herts.ac.uk

Appendix 13: Ethical approval

To: Nadine Oladokun

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

Your UH protocol number is: **0615 STa HSET 2026**
This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval - Ethics Forms.

This ethics approval expires on 30/09/2026

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority prior to implementing any changes. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

Adverse circumstances
Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team
ethicsadmin@herts.ac.uk

Appendix 14: Debrief

University of Hertfordshire UH Ethics Committee

Research Participant Debrief

Study title: Young people's experiences of being supported with Sickle Cell Disorder within their educational setting

Thank you for your participation in this study! Your participation is greatly appreciated.

What is the purpose of this study?

The research aimed to explore young people's experiences of being supported with Sickle Cell Disorder within school. By exploring these experiences, we hoped to understand what is important for young people, what they value, what things are working or not. This will help to not only understand the experiences but to contribute to conversations in policy, recommendations and positive change.

What if I was impacted by the study?
This research asked about young people's experiences of support in relation to their Sickle Cell Disorder in school. Speaking about these experiences can be distressing in relation to any difficulties experiences. You may find it helpful to contact one of the organisations you were previously notified of. Please see the contact details again for below reference.

The professional code of contact means that I (Nadine Oladokun) cannot individually support participants in the study, which is why we have created the list below should you require further support.

If you feel that your taking part has highlighted particular physical or mental health difficulties that you would like support with, please get in touch with the below organisations.

- Your GP
- Your SCD service (if applicable)
- Sickle Cell Society https://www.sicklecellsociety.org

  Helpline: Mon & Tue: 07842 245 980; Wed: 020 89617795; Thurs & Fri: 07809736089. Opening hours: Mon-Fri 9-6pm (excl bank holidays)
- Central Bedfordshire SENDIASS https://cbsendiass.org/support/sickle-cell-society/ 0300 300 8088, sendiass@bedfordshire.gov.uk/parentpartnership - drop in sessions for support or advice
- Contact a family https://contact.org.uk/conditions/sickle-cell-disorders/

Helpline: 0808 808 3555 Mon-Fri 9:30-5pm

At the end of the study, the researcher will ask if you would like to know more about this study or be sent the study results, which will be sent in a leaflet.

Contact details

Researcher: Nadine Oladokun, n.oladokun@herts.ac.uk
Supervisors: Dr Megan Maidment, m.maidment@herts.ac.uk
Dr Angela Kirby, angela.kirby11@nhs.net

Thank you again for your participation.

Appendix 15: Interview schedule

Young people's experiences of being supported with Sickle Cell Disorder within their educational setting.

Initial checking in questions:

- How are you today?
- How are you feeling? – this question will be asked throughout the interview
- Are you in any pain, discomfort or are you feeling tired?

Participants will be reminded to take a break if they want to and will be asked to bring anything that will make the interview as comfortable as possible e.g. bringing, food or snacks, water or a pillow.

Initial interview questions:

- Can you tell me what a usual day tends to look like for you at school?

Prompts: lessons, activities, lunch, breaktime

- Can you describe a favourite subject you have (if you have one)?

Prompts: physical education, art

- What is a really good day like for you at school?

Prompts: feeling energetic, being with friend, no SCD symptoms

- Can you tell me about someone at school you like spending time with?

Prompts: friends, teachers.

Lived experience of sickle cell in education

- Can you tell me about what it's like to be a student while living with sickle ell?
- How does sickle cell affect you during the school day?
- Can you describe a time when sickle cell had a big impact on your learning or attendance?

Prompts

- How did that feel at the time?
- How does your body feel? And how do you manage pain or tiredness if it starts at school?
- What was going through your mind?
- Missed lessons prompt if applicable

Experiences of support

- When you think about "support" in school, what does that mean to you?
- Can you tell me about a time when you felt supported at school because of your sickle cell?

- Who, if anyone, has been most supportive of you in your education?

Prompts
- What did they do that helped? E.g. extra help or adjustments or listening
- How did that support affect you?
- Flexible deadlines, homework, physical education

Experiences of lack of support
This question will be participant led and handled softly
- Have there been times when you felt unsupported or misunderstood in school?
- Can you describe an experience where the support you needed wasn't there?

Prompts
- How did you respond to that?
- What impact did that have on you as a student?

Relationships with staff and peers
- How do teachers respond to your sickle cell?
- What has it been like explaining sickle cell to people at school?
- How do other students treat you in relation to your sickle cell?

Prompts
- How comfortable do you feel talking about it?
- Has that changed over time?

Identity, independence, and self-advocacy
- How do you see yourself as a student?
- In what ways do you feel sickle cell has shaped who you are in school?
- How do you decide when to ask for help or support?

Prompts
- What makes that easy or difficult?
- How do you feel when you have to explain your needs?

Emotional impact
- How does receiving (or not receiving) support make you feel?
- How do these experiences affect your confidence or motivation in school?

Prompts

- What helps you feel better at school?

Looking back and looking forward

- Has your experience of support changed as you’ve got older?
- What have you learnt about yourself through these experiences?
- What kind of support do you think would make the biggest difference for students with sickle cell?

Closing question

- Is there anything else about your experience of education and sickle cell that feels important to share?

Appendix 16: Table 13 Worked Transcript for Ebuka

Theme	Interview	Exploratory notes
	I: And can you tell me about a time when you felt supported at school because of your sickle cell?	
Lack of support **SCD affects school attendance** **Falling behind peers**	**E:** When I felt supported, UH. My head of year, I was off for lots and lots of my French lessons and since year seven I didn't do a single assessment for French. So what she helped me do is she took me out of my lesson right after all my other classmates had done their PPAs assessments.	**Thinks about this question, perhaps because support has been lacking. Missed a lot of school due to SCD. Wonder how it made him feel missing a lot of lessons? And how it affected him? Potentially behind his peers.**
Catch up support available		**Support from his teacher to catch up.**
	E: She done it with me, so I was there and I tried doing my assessment, so she was just helping me with that.	
Lack of support and understanding from staff	**I:** That sounds really nice that she was there to support you. And if you have any homework or deadlines, are the school quite flexible? So do they give you some extra time sometimes?	**Lack of support from teacher and understanding and flexibility.**
Range of support from senior staff	**E:** Yes, depending on the teacher, like I said before, like with my engineering teacher, because he wouldn't give me extra time, he would just be rude to me.	**Highlights a range of support but most seem to be more senior staff. Handful of school staff support perhaps highlighting the lack of support.**
Understands the importance of food/nutrition for health		**Dislikes school food, but this affects health.**
Support from head of year	**I:** Okay. And if you think about the support you've had at school since year seven, who has been the most supportive to you?	**Good communication and care from head of year. Wondered how he felt collapsing if in front of others?**
	E: Well, my medical teacher in primary, Miss X Then my head of year in year 7, Miss X and then my assistant head of year now, and my head of year Mr. X and Miss X, because a couple of weeks ago I actually collapsed because I don't really like eating in school and stuff and I just don't really eat. So we thought that's why we collapsed. And my head of year actually sent my mum a voice note just checking if I was all right, asking how I've been and stuff. And my assistant head of here, he actually took me out of class just to	**Support provided, feels supported and heard.**
Differences in understanding in regular v non-regular staff		**Normal teachers having a better understanding of his needs compared**

Lack of understanding from teachers	check on how I was doing. **I:** Oh, that's really kind. That's really nice. I'm sorry to hear that you collapsed, but it's good that you're feeling better. UH. Okay. And so we've spoken about support and you've actually spoken about lack of support, for example, your engineering teacher, how he's been with you. So you don't necessarily need to repeat that or answer. But if there's anyone else, you might be able to answer. So have there been times where you felt **E:** Yes, sometimes we have cover teachers and some of those cover teachers won't understand what I'm going through because they're not my normal teachers. So sometimes they'll be rude. And then sometimes, like, because... All my other teachers are sometimes are used to having students who don't have any hidden diseases They sometimes lash out on me, like only a little bit, because I'm not meeting all of their deadlines. **I:** Yeah, okay. And how does it make you feel when you have these experiences from these teachers that aren't really supportive? **E:** Well, I'm disappointed because even when I explain things to them and they don't listen it's annoying because I've explained to you what's happening, I've explained to you how it's affected me and you're still saying I can do it, like I'm perfectly fine. **I:** Okay, and this might be very similar to the question I just asked you, so you can just let me know. But can you describe an experience where the support you needed wasn't there? **E:** UH. Sometimes in... Like, let me think, RE. So one of my teachers, she's, because my original teacher, she went on maternity. So now we have a history teacher who's teaching us about RE	**to cover teachers. Wonder how it makes him feel?** **Frustration. Teacher's lack of understanding of SCD and its management.** **Strong words/juxtaposition lash out on me, only a little bit….** **Being punished for having SCD.** **Wonder how it affects him?** **Feels sad due to teacher's treatment. Not taking his SCD seriously. Change in tone of voice. Sounds less upbeat.** **Frustration, disappointment.** **Appears frustrated perhaps due to a teacher not teaching on subject matter.** **Wonder how he feels having all the passes?** **Emphasizes "just" perhaps highlighting how teachers talk to him.** **Highlighting lack of support or understanding of SCD.** **Highlights a lack of support across permanent/more regular teacher and with cover teachers. When speaking about his engineering teacher, change in tone of voice and facial expression like frustration.**
Lack of understanding		

	So because I have to drink a lot of water and fluid, I have a toilet pass, I have a medical pass. I have a lot of passes. And sometimes if it's like just been break. and like 20, 10 minutes after, I'm drinking a lot and I need to go toilet again. Sometimes they get really annoyed with me and start saying, oh, you've just had break, why can't you wait? **I:** Yeah. And have you seen that across maybe different teachers who might not know you as much or is it just within like your RE teacher? **E:** Nothing. Probably with like two other teachers, like my engineering teacher. Yeah, probably just my engineering teacher as well. –	

Appendix 17: Table 14 Initial themes from the five transcripts

Ebuka: Initial themes generated from analysis of transcript	Adaeze: Initial themes generated from analysis of transcript	Damilola: Initial themes generated from analysis of transcript
Impact of weather on health Lack of confidence The fluctuation of SCD Teachers lacking understanding Teachers discrediting feelings of pain Ignorance towards SCD Explaining himself to staff Paying the price because of response towards SCD Interest in physical based activities despite its impact Pushing himself to his limit Pressure from others to compete Understanding how to manage his needs Comparison of abilities with peers The impact of SCD on school attendance Flexible approach from school Social isolation A desire to be heard by teachers Lack of visibility of SCD Ignorance towards SCD in school Wanting to be normal Attempts to conceal SCD Trying to keep on top of subjects	Lingering pain Pain managed by medication Striving to be seen for more than her SCD The value of supportive friends Working twice as hard as others Lack of flexibility in school Desire to achieve well academically Manages her pain independently Limited in what she can take part in Understands her body's limitations Avoids pushing herself Social isolation from peers The detrimental impact of cold weather on SCD Awareness of pain triggers The impact of SCD on school attendance Catch up support available The impact of SCD on grades Pressure and lack of understanding from teacher Enduring pain Negative assumptions by teachers Variety of support in place Support has increased Lack of communication among staff Determined to help others with SCD Collaboration with school and family School nurse is supportive Aware of strengths and capabilities Misunderstood by peers SCD used against her negatively Media's role in SCD misconception Importance of academia and not falling behind Pushes herself Proving herself Listens to her body Values learning Difference between permanent and supply teachers Reasonable adjustments Refrains from speaking about SCD Lack of understanding from peers Future planning Shame over SCD The challenges of asking for support	The value of friends Spontaneity of pain Dealing with pain Normality is far from him Comparisons between the self and others The impact of SCD on school attendance Overexerting self Judgemental response from teachers and family in the Netherlands Awareness of difficulties from teachers Feeling supported The relationship between the weather and SCD Reasonable adjustments Falling behind on homework deadlines Lack of understanding from peers Explaining self to others Limitations of medication Others lack motivation to understand Striving to be treated like others Confidence influenced by family Higher pain tolerance
Shola: Initial themes generated from analysis of transcript	Chidinma: Initial themes generated from analysis of transcript	
Forced to do things Peers lack knowledge Pain triggered by physical activities Pain and social isolation School attendance affected Lack of support to catch up Good communication from school Reasonable adjustments Support is uplifting Lack of school planning Teachers lack knowledge Enduring pain Disclosing SCD depending on closeness	Listening to my body Value of friendships Limitations of medication Pain affected attendance Social isolation Faith in God Brother's support and stability Catch up support not available Perseverance Supportive teachers Teacher's lack of understanding Restricted access for basic needs Having to convince teacher's Choosing who to share SCD with	

Confidence increased by teachers Feeling isolated with SCD Listens to his body Comparison of self to others Seeing self as fragile Doesn't want to stand out Regretting his silence in his younger years	Negative judgement from others Confidence has increased over the years Strengths gained with SCD Feels bad missing out on peer interaction Fees unsafe asking teacher for support More support with age	

Appendix 18: Table 9 Clusters

Shola's personal experiential statements:

Cluster A: **1) The impact of others lack of understanding of SCD** - Emotional exhaustion of enduring pain as a result of lack of knowledge - The internalised guilt compounded by low self-esteem – pain
Cluster B: **2) Confidence as a mechanism of lived experience of SCD** - The decisions made as a child affect who I am today - Support validates my experience – confidence - Friends showing up as allies – interest in SCD - Speaking to peers
Cluster C: **3) Managing his needs** - Prioritising health and rest at the expense of isolation and alienation - Understanding my limits to avoid a pain crisis - Toilet pass

Appendix 19: Table 15 Working personal experiential statements from individual participants analysis

Theme 1: Challenges of having an illness others cannot see	Quotes
Reduced understanding and empathy from teachers	**Adaeze:** "So it's just like, are you not reading with from the system? Like, do you just not bother to like...Try and understand and know about your students and the stuff they have" "You obviously don't understand if you're telling me that my pain is not that bad that I was able to wait just for a few hours" "But if it's a supply teacher, I'm having to like fully convince them. They're like, oh, show me your pass, show me your pass" **Damilola:** "So sometimes when I get pain and like I'm studying or something, I get pain. They're like, it's too convenient. And they tell me that I'm pretending"
Pain and fatigue dismissed as laziness by peers	**Adaeze** "Like, if I'm not in, my friends will be like, oh, you were too lazy to come in, or why didn't you come in for a full week? Stop being lazy"
Theme 2: Internal conflict experienced due to SCD	
Masking and enduring pain as a means of appearing normal	**Adaeze:** "Sometimes I don't. Tell everything about my sickle cell because I could literally be in so much pain at school, but I was still act normal around my friends because I don't want them to like... See me when I'm at like my lowest and my weakest" **Damilola:** **"**It makes me feel like I'm not normal"
Fear of judgement due to missing school	**Adaeze:** "Mm. I'm kind of just thinking how they'll see me after I ask, like, will they see me as kind of less than because I've needed to come and like ask them how to do something because I miss that lesson"
The challenges of missing out on social interaction	**Adaeze:** "on days I'm sick and I can't come into school and my friends are just at school without me and they'll be telling me the stuff that happened while I wasn't there and I'll just feel kind of like bummed out because I wasn't there to experience it with them" **Shola:** "If, say, for they're playing a game, but then I want to like leave it early because, like, I don't feel well like I feel tired or whatever, and they keep going on, don't want to like talk, whatever, they just keep playing"
Theme 3: Things that are important to me	
Resilience and perseverance as a result of SCD	**Adaeze:** "So I'm not always comfortable speaking in like public places or in front of a lot of people, but I was able to put that aside because of my like resilience and the fact that I wanted to educate people about sickle cell so bad that I was able to put all my anxiety beside and just speak" **Chidinma:** "I actually didn't know like I would have confidence like the one I had, the one I have now. He's like, I used to be a shy person"
Pushing through my challenges to succeed and achieve	**Adaeze:** "So during tests I kind of had to work two times as hard to finish at the same time as everyone else – because during tests I do get quite tired or my hands will start cramping up and I'll be in pain, but I need to kind of like just push

	through it to finish with everyone else and do a good job on my test” **Damilola:** “When I get, when I don't get support, it's just tough it out of you until she's here, tough it out until she's here” **Ebuka:** I overestimate myself sometimes, like sometimes I'll go in races and because I'm 34. one of the fastest in the school, I won't. Well, slow down fast enough
Advocation as a means of social justice	**Adaeze:** “I want to be able to talk about my personal experience with sick cell and I want to be able to kind of be a voice for other people with sick cell as well” **Shola:** “is trying to make me like speak to other people about the sickle cell as well, like not even like my friends, probably the teachers as well”

Appendix 20: Table 16 Group experiential themes, sub themes and supportive quotes across participants

Silently fighting an invisible illness others cannot see at school	**Symptoms dismissed as an attempt of truancy by adults**	**Ebuka**	"You have hands, you're able to do it".
		Chidinma	"When I drink water and then I tell them I want to go to the toilet, they won't let me go. They'll just be like, oh, I think you want to go on your phone in the toilet".
		Damilola	"So sometimes when I get pain and like I'm studying or something, I get pain. They're like, it's too convenient. And they tell me that I'm pretending".
	Lack of understanding from peers	**Adaeze**	"Like, if I'm not in, my friends will be like, oh, you were too lazy to come in, or why didn't you come in for a full week? Stop being lazy". "…When Supacell came out, I felt like it just made everybody misunderstand so much more because people were like, oh, you have supercell".
		Damilola	"You know, when I tell them that I'm having pains, you know, they laugh and then they now like, wish me well". "I told them I have sickle cell and they're like, super cell. Do you have powers? What powers do you have? And it's like, ha ha ha".
		Shola	"Say for I'm getting forced like, say for other people running, they want me to run like, and sometimes they don't even, they don't know about the sickle cell, so, like, like, I can't run properly".
	Pain endurance	**Adaeze**	"So during tests I kind of had to work two times as hard to finish at the same time as everyone else because during tests I do get quite tired or my hands will start cramping up and I'll be in pain, but I need to kind of like just push through it to finish with everyone else and do a good job on my test".

		Damilola	"I don't like it again because I have to still like be in that pain whilst having to wait until the lesson finishes".
Striving for a non-totalising view of living with SCD at school	**Chasing normality despite physical limitations**	Ebuka	"And I like to be athletic and I like to act like I don't have sickle cell".
		Adaeze	"Sometimes I don't tell everything about my sickle cell because I could literally be in so much pain at school, but I will still act normal around my friends because I don't want them to like... see me when I'm at like my lowest and my weakest"
		Damilola	"I'm doing my best studying when I can at home, you know, but like, again, makes me feel like I'm not normal".
	Positive aspects of identity	Adaeze	"More perseverance than others because... Even on a day that I might be sick and unwell, I'll still come into school and I'll push through because I want to have my education. I want to be like known for my personality, my resilience, my intelligence. I don't want to be like remembered by my condition".
		Chidinma	"I feel bad in some aspects and I feel good in some aspects because like it also helps you build your confidence over time and know that you're strong and smart".
	Advocating for SCD	Adaeze	"I want to be able to talk about my personal experience with sickle cell and I want to be able to kind of be a voice for other people with sickle cell as well…So like a few months ago, I participated in the Jack Petchey Speak Out competition, and I did my speech on sickle cell, so I'm kind of becoming like more open to telling people about my sickle cell and just kind of educating people on it".
		Shola	"Is trying to make me like speak to other people about the sickle cell as well, like not even like my friends, probably the teachers as well".
Community, support and connection in education	**Safety within friendships**	Damilola	"And like, that's another reason why I really love my friends, both the ones online and in

			real life, because like, they don't treat me any differently". "But like with my friends, but like when they see that it's getting rough, you know, it's getting too much. That's when they start looking out for me, you know, because they don't want me to get hurt or sick".
		Chidinma	"When I actually came to the school, they helped me settle down and then they also like, they have been good friends and they also chat well with me as well…it was when my friends gave me their fidget toys to, like, hold onto, 'cause I wasn't so much, but I couldn't speak to anyone at that point".
	Feeling left out	Adaeze	"On days I'm sick and I can't come into school and my friends are just at school without me and they'll be telling me the stuff that happened while I wasn't there and I'll just feel kind of like bummed out because I wasn't there to experience it with them".
		Shola	"Like I feel tired or whatever, and they keep going on, don't want to like talk, whatever, they just keep playing, whatever…I don't like it".
		Chidinma	"I feel bad in some aspects and I feel good in some aspects because like it also helps you build your confidence over time and know that you're strong and smart".
Educators adapting care according to individual need	**Reasonable adjustments catered for SCD symptoms**	Ebuka	"So because I have to drink a lot of water and fluid, I have a toilet pass, I have a medical pass. I have a lot of passes".
		Adaeze	"They've started to understand, they have my care plan in place, they've given me a lot of support, like I have a lift pass and a toilet pass and a uniform and medication pass".
	Support from teachers	Ebuka	"But that's why most of my teachers, they'll put up like we have a Google classroom, so they'll put up work and revision on there for me for when I'm able to do it".

		Adaeze	"Like we went over my care plan with my sickle cell nurse and the school nurse and the SEND leader".
		Damilola	"She, like, she was always looking out for me, you know, especially like usually I don't like wearing my blazer because it's either too hot or like it's uncomfortable. So usually when she's out and she sees me without my blazer, she tells me to put it on, like, because like she's worried that the cold will get to me, you know".
		Chidinma	"The really good ones, um, they help when you like, um... sick or uncomfortable, they help tell you things, they ask you what you want and what you don't want. Or like when you get tired and you know you need to rest for a bit, they just lower the voice and things like that".
	The vital role of "medical" in physical pain management	Ebuka	"Probably if I need medication, like if I'm in pain, I go down to my medical room".
		Adaeze	"I think if there was to be anyone, it would probably be the school nurse because she's probably the person who has the most knowledge about sickle cell. Now at this point, when I do go to get medication, she just understands straight away and if I do tell her that I'm not feeling well, that I need to go home, she does just send me home".
		Shola	"One of the medical teachers, like they could tell straight away what was going on with me".

Appendix 21: Table 17 Excerpts

Date: May 2025 Consultation: Given a different perspective of sickle cell from an expert by experience. Made me realise how far removed I am from this area in terms of language e.g. diagnosis instead of disease. Researchers without lived experience are so far removed from research, hence very important to have experts by experience involved to shape research.
Date: November – December 2025 SLR Thematic synthesis: difficult to independently think of themes when reading research that has already developed themes. Being mindful to not allow pre-determined themes to influence my themes. Brought to supervision.
Date: January 2026 Coding Spirituality paper (SLR) – Some participants were Christians. I easily coded and interpreted this based on my own Christian faith e.g. understanding scriptures however my understanding of scripture possible led to biased interpretations and not how participants meant it in their context. Found myself having alternative view of scripture e.g. this person has stated this however I think it could mean this. Once I realised this I paused and tried to stick to what they were saying.
Date: February 2026 Consultation with adolescents: I thought I knew what young people wanted but their thoughts on the poster e.g. too much info and lighter colours plus their thoughts on interview adjustments e.g. cushion, snacks was very helpful. This highlighted the importance of input from a relatable demographic.
Date: March – May 2026 Interviews – feeling heavy emotionally, hearing young people's stories and thinking I'm not doing enough. Was very touched by young people's stories. Reflected on my privilege in being able to continue with my life smoothly whereas they experience pain etc, uncertainty.
Date: April 2026 Participant from Nigeria – very painful experience. My facial expressions demonstrated my feelings; he mentioned not wanting to be treated any different – made me realised the importance of finding a balance in my expressions and how I verbally respond. During this time Reform MP's comments about Nigerians filing potholes. Although this did not come up in the interview, it was uneasy interviewing knowing this.
Date: March 2026 Doing interviews and thinking participants are bored – although this was never mentioned, I sped up some interviews instead of getting more in depth answers. Relates back to how I feel when people are helping me out, although participants found it meaningful to have someone to speak to.

Date: May 2026 Data analysis: I felt influenced by SLR themes when analysing participants' transcripts and had to take a step back and remind myself.
Date: May 2026 One participant spoke about faith, and I felt like I could relate. When she didn't report difficulties initially, I could relate through her position on faith. I felt divided as a Christian to accept this when she initially reported that she does not have difficulties but as a researcher I wanted to explore this further without trying to push her to say something negative.
Date: May 2026 Interviews: Three participants were Nigerian. This was sad to see as a Nigerian myself. All participants identified as Black. Would often think about impact of race on experience although this never came up.
Date: May 2026 Interviews: I was thinking about doing more of – e.g. publishing research, would love to share strategies to parents however this isn't part of my ethics. One participant lacking confidence to ask for help due to disrupting lesson and how I can help.
Date: March 2026 Challenge of role as a researcher but bringing qualities of a therapist to interviews and trying to find balance. Supervision has helped to check any bias.

Appendix 22: Research summary

YOUNG PEOPLE'S EXPERIENCES OF BEING SUPPORTED WITH SICKLE CELL DISORDER IN SCHOOL

Nadine Oladokun

INTRODUCTION

In England there are around 17,000 people living with Sickle Cell Disorder (SCD). People with SCD experience pain, tiredness and infections. For young people these difficulties can affect going to school, being with their friends and taking part in activities.

This research aimed to understand young people's experiences of being supported with SCD in their education setting.

What happened?

5 Young people with SCD living in England completed an online interview. They were asked questions about having SCD and being in school, support, relationships with staff and peers, independence, emotions and their future






What did young people say in interviews?

Four themes came up from young people's interviews which are shown below:

1) Silently fighting an invisible illness others cannot see

- Young people spoke about being in pain and not always being believed or giving support.
- So, young people can explain to teachers what it's like to have SCD, if they feel comfortable.

2) Wanting to be known for more than their SCD

- Young people wanted to be seen as "normal" and their strengths to be focused on instead of SCD.
- So, young people can remind themselves of their strengths and qualities, especially in hard times.

3) Community, support and connection

- Young people appreciated support from their friends and "medical" who understood them and did not question them when unwell. Supportive teachers were important to young people. When a young person missed school because they were unwell, this made them feel sad.
- Young people should be supported to catch up with school work when unwell. They can be given work to do available online e.g. google classroom. Young people can try to stay connected with friends e.g whatsapp if they are able to do so.

4) Individual care

- All young people had passes e.g. a toilet pass or break pass, which helped them with their needs e.g. pain. Care plans were helpful and seen as positive sources of support.
- Young people should be at the centre of their care plan so their voices are included. Care plans should be looked at frequently so they are up to date.

Final comments..

Thank you to all of the young people who took part in this research. Young people provided detailed information about their experiences in school. They shared the difficulties and positive experiences in school and had recommendations for changes. This research has put together recommendations for schools and health care professionals supporting young people with SCD.

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