“It really kind of like cuts my existence into two”:

An Interpretative Phenomenological Analysis of the Experience of Adults with Sickle Cell Disease receiving curative Haematopoietic Stem Cell Transplantation (HSCT)

A thesis submitted to the School of Social Sciences and Professions of London Metropolitan University in partial fulfilment of the requirements of the Doctorate in Counselling Psychology

by

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DECLARATION

I declare that all the information in this doctoral thesis is my own original work, except where otherwise stated.

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Abstract

Background: Sickle cell disease (SCD) is the most common single gene disorder in England. At present, Haematopoietic Stem Cell Transplantation (HSCT) is the only cure, and as of 2020, these have been funded for adults with SCD by the National Health Service (NHS) in England.

Rationale: The provision of psychology support is deemed important for patients undergoing HSCT, as studies have found a high prevalence of psychological distress is reported (Amonoo et al., 2019). Most research into HSCT have been in relation to haematological malignancies. I reasoned that further research adopting an explicitly psychological focus would be valuable in understanding the lived experiences of HSCT recipients with SCD and how they can be supported psychologically through this major life transition.

Methodology: Six adults with SCD participated in semi-structured interviews regarding their experience of HSCT. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (Smith et al., 2022).

Findings: The analysis resulted in three Group Experiential Themes: (1) 'Leaving the Inferno' – details how the worsening burden of SCD over time influenced participants in making the decision to proceed with HSCT, despite the risks, with all hoping for a more 'normal life'; (2) 'Travelling through Purgatorio' – documents the challenging experiences participants had, how they coped, and their attitudes towards psychological therapy as a way of supporting them through HSCT; (3) 'Journeying towards Paradiso' – focuses on participants' progress towards the more 'normal' life they had hoped for after HSCT and ongoing adjustment to life without SCD. Crystal Park's Meaning-Making model (2010) was selected as a theory that could help in understanding the way in which participants' beliefs and goals developed through a life lived with SCD guided their interpretation of their HSCT experience.

Implications: Psychological therapies that can facilitate the process of meaning-making would appear potentially helpful in supporting people with SCD through HSCT and adjusting to life afterwards. The importance of making therapy culturally sensitive is emphasised, with African Psychology being a strengths-based approach that may be particularly relevant. Finally, a relational approach to supporting people with SCD through HSCT at the level of the healthcare system as a whole is argued for, extending the principles of Trauma-Informed Care towards building genuine trust with recipients who may have experienced health and race-based stigma and discrimination.

Reflective statement

My decision to complete a Top-up Doctorate in Counselling Psychology came 13-years after qualifying as a Counselling Psychologist in 2009 via the independent route. In order to explain my motivations for doing so, I think it would be helpful for the reader to have an understanding of my professional experiences in the preceding years. After qualifying, I worked for around six years within an Improving Access to Psychological Therapies (IAPT) service, becoming accredited in Cognitive Behavioural Therapy (CBT) and Interpersonal Psychotherapy (IPT), whilst also developing competencies and experience in running Mindfulness-Based Cognitive Therapy (MBCT) groups. Over time, I felt increasingly depleted by carrying a high caseload of clients and disillusioned with the emphasis on targets inherent within IAPT. The only route for progression to higher banding was to become increasingly involved in management and supervision, which I felt would take me further away from developing clinical competencies and growing as a therapist. At that point in my career this is what I most craved.

In 2015 I therefore took advantage of an opportunity to begin working in acute hospital settings with people with physical health conditions. I relished the relative independence and autonomy of working in health care settings and being part of a multidisciplinary team, where I felt a fuller range of the competencies of being a counselling psychologist could be applied. Over the past nine years I have worked in a young adults' rheumatology service, with people with motor neurone disease, and currently in an acute stroke unit. One constant has been that for all of this time I have worked with people with Sickle Cell Disease (SCD), and have been employed in three separate London Hospital Trusts, establishing new psychology services in two of these. I have found working with people with SCD fascinating, requiring skills in delivering psychological therapies, knowledge of neuropsychology and pain management approaches, and a well-developed awareness of socio-cultural contexts and ways in which they intersect.

Given the fact the vast majority of people with SCD are Black, this has prompted me to learn more about African and Caribbean cultures so I can be attuned to the ways I may need to tailor therapy towards their needs and values. I have long held a passionate interest in understanding different cultures and religions, with particularly formative experiences having been spending time teaching English in China and marrying my wife who is from Mauritius, of Indian heritage, and a practicing Hindu. Such experiences have enhanced my sensitivity to culture and respect for different worldviews and values. I have also increasingly come to acknowledge my own 'whiteness' (Ryde, 2009; 2011) and relative privilege and

power in relation to people with SCD, as well as develop a willingness to hear and engage with narratives around race, ethnicity, and discrimination (Nkansa-Dwamena, 2017). This is very much in keeping with Counselling Psychology's values of recognising power dynamics in different contexts, and appreciating the diversity of client groups, especially in preventing stigmatising and discriminatory practices (BPS, 2005, BPS, 2019).

I had contemplated applying for a Top-up Doctorate in Counselling Psychology for several years, but had hesitated due to the lack of a clearly formulated research proposal and a combination of family and financial commitments. Having completed my training in Counselling Psychology via the Independent route, the fact I do not have the title of 'doctor' was one way I have been marked out as different from the other psychologists with whom I have worked. While a part of me is rather contemptuous of the vanity titles such as 'doctor' can bestow in creating an impression of status and superiority, I did continue to feel a degree of incompleteness at not having fulfilled the doctoral level research component of training, which is so much a part of the competencies and identity of being a Counselling Psychologist (BPS, 2019; Henton, 2016).

By 2021 the timing finally felt right to proceed with a doctorate, as my personal circumstances had become more conducive to doing so. I felt doing research related to SCD would be an excellent opportunity to consolidate my knowledge on this subject and extend my academic abilities, but uncertain of what the focus of this should be. In 2020 the NHS made Haematopoietic Stem Cell Transplantation (HSCT) available to adults with SCD as the first curative treatment. This presented me with a potential research topic that was intensely fascinating, as I tried to imagine what it would be like for someone to be free of a life limiting disease they'd had since birth and were expecting to have until the day they died.

Since 2020, I have been part of conversations with NHS colleagues about how best to support people with SCD before, during and after HSCT. This has included within the British Psychological Society's (BPS) Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia, and a newly created Stem Cell Transplant Psychological Professionals Network (SCTPPN), which aims to support, learn and share best practice. I contributed to the development of a service operational policy around the conducting of Pre-Transplant Psychological Assessments at one of the hospitals where HSCT for SCD takes place, and have also been a psychology representative at the regular meetings of the National Haemoglobinopathy Panel, where each SCD referral for HSCT in England is discussed by a multidisciplinary group of experts (NHS England, 2019a).

I have never worked therapeutically with anyone who has gone through HSCT however, and so my knowledge of what this entailed was quite limited, so in this respect I was relatively open-minded about what I would discover about the process. I was inevitably influenced by my knowledge and experience of working with people with SCD, and did expect it would be an event of considerable existential significance to recipients, affecting their sense of identity. I also imagined they would feel liberated from the stigmatizing effects of having SCD (Bulgin et al., 2018), expecting they would speak about this and the ways this may have altered their relationships with family, friends, and society at large.

Given my background working with people with SCD, I felt confident that I would be capable of exploring in depth the experiences of HSCT recipients had gone through. My discovery of Interpretative Phenomenological Analysis (IPA) as a methodology inspired me greatly in identifying a way of conducting research that resonated with my long-standing interest in philosophy, particularly existential-phenomenological thinkers such as Martin Heidegger, who I found intriguing yet obscure. It also appeared to overlap considerably with Counselling Psychology as an approach rooted in phenomenology and existential philosophy (Kasket, 2017).

In 2022 I prepared a research proposal and was successful in securing a place as a top-up student on the Doctorate in Counselling Psychology at London Metropolitan University. I was exhilarated by this, feeling not only did I have a topic sufficiently interesting to keep me engaged throughout the challenging process of completing a doctorate, but I also thought it would be of importance to others to discover more about what this experience is like for people with SCD. I hoped the data generated would be valuable in considering how to help people with SCD psychologically as they undergo HSCT and adjust to life afterwards, and therefore be of considerable relevance to the profession of Counselling Psychology.

CHAPTER 1: INTRODUCTION

1.1 What is Sickle Cell Disease (SCD)?

Sickle cell disease (SCD) refers to a group of inherited blood disorders affecting the haemoglobin molecules of a person's red blood cells (Ware et al, 2017). The haemoglobin molecule is what gives rise to the red appearance of blood cells, and its primary role is to carry oxygen from the lungs around the body via a network of blood vessels. Haemoglobin contains two alpha globin chains and two beta globin chains wrapped around four iron atoms. Usual haemoglobin is referred to as haemoglobin A, abbreviated to HbA, while sickle haemoglobin is referred to as haemoglobin S, abbreviated to HbS. The gene that encodes for HbS is located on chromosome 11, and results in one alteration in the molecular structure, with the amino acid valine replacing the amino acid glutamine at point six of the beta-globin chain (Dyson, 2019).

People inherit two copies of the gene for haemoglobin, one from each parent. If one of these genes codes for sickle haemoglobin (HbS) while the other codes for normal haemoglobin (HbA), then the person has Sickle Cell Trait (HbAS) and will not normally experience any symptoms. Haemoglobin SS (HbSS), commonly called sickle cell anaemia, is where a person inherits two copies of the sickle haemoglobin from their parents and is usually the most severe form of the disease, accounting for around 70% of SCD. Haemoglobin SC (HbSC) accounts for around 20% of SCD, and is where the individual inherits one copy of the sickle haemoglobin along with one for the haemoglobin C mutation (HbC) in which glutamine is replaced not by valine but by lysine. There are further types where a gene associated with sickle cell is co-inherited with a thalassaemia gene or another haemoglobin variant.

In circumstances of dehydration, cold, heat, or stress, the red blood cells of a person with SCD become deoxygenated and the sickle haemoglobin inside them crystallizes into long twisted chains. This process causes the red blood cell membrane to become distorted, resulting in the characteristic sickle shaped blood cell, resembling the agricultural cutting tool that bears the same name. These abnormally shaped red blood cells become stiff and stick together leading to blockage of narrow blood vessels and blood flow, causing excruciating pain and tissue damage to the part of the body that has been deprived of oxygen. This process is referred to as a vaso-occlusive episode, or more commonly, a sickle cell crisis (Howard & Telfer, 2015; Kato et al., 2018). Dyson (2019) argues the sickle shape has been over-stressed in comparison to other key mechanisms in SCD, such as inflammation, chronic damage to cell walls, and the fact sickled red blood cells typically only survive 10 to 20 days before breaking up (haemolysis), as compared to the usual life span of

120 days for normal blood cells. This results in a shortage of red blood cells (anaemia) in the person's body, which is unable to get sufficient oxygen and is therefore prone to fatigue (Chaturvedi & DeBaun, 2016).

Pain is the hallmark and chief symptom of SCD, with it being described as 'unbearable', 'agonising', 'excruciating' and 'penetrating', and compared to a "hammering inside your bone and drilling" and "being set on fire continuously" (Coleman et al., 2016). SCD can be life threatening, causing multiple problems such as severe infections, strokes, chronic fatigue, acute chest syndrome, delayed growth and organ damage, with the kidneys, lungs, brain, liver, spleen, bones and eyes especially affected (Howard & Telfer, 2015; Ware et al, 2017; Sickle Cell Society, 2018). Chronic pain is also very prevalent, which may be due to tissue and organ damage, central sensitisation or neuropathic pain (Darbari et al., 2014; Dampier et al., 2017). Managing such chronic pain can result in repeat prescriptions for long-term opioid use, which may be fraught with problems, such as opioid induced hyperalgesia, tolerance, dependence, constipation, endocrine changes, nausea, vomiting, respiratory depression, and the risk of death (Gupta et al., 2015; Ruta & Ballas, 2016).

1.2 A brief history of SCD

The history of SCD stretches back many thousands of years, and there are two competing models of the origins of the sickle gene. The multi-centric model proposes the sickle gene mutation arose within the last few thousand years in five separate geographical locations, four being in Africa, and a fifth having originated in India. The uni-centric model posits a single occurrence of the mutation occurring much earlier. Recently, Shriner and Rotimi (2018) claim to have found strong support for the uni-centric model after they analysed the genomes of nearly 3,000 people, and traced the sickle gene back to one mutation that occurred approximately 7,300 years ago. They propose this happened either in the area that is now the Sahara Desert, but which at the time was lush and fertile, or in West / Central Africa.

The common geographical factor that accounts for the distribution of people with SCD is that there is a history of malaria, or migration from a malarial area. Those who inherit one copy of the gene associated with sickle cell (sickle cell trait, HbAS) are relatively protected from death from malaria, especially for infants who have not had time to build up resistance to this parasite. When infected, this causes the red blood cell to sickle, be destroyed, and cleared by the immune system, before the parasite has had time to breed and infect other red blood cells. People who carry two copies of a gene associated with SCD, in particular

sickle cell anaemia (HbSS), are not protected, however, and are extremely vulnerable to early death from malaria (Williams & Obaro, 2011). Over time, the number of people with genes associated with sickle cell reaches a balance between the increased reproductive fitness of those who are sickle cell genetic carriers, and the early deaths of those with SCD, providing an example of balanced polymorphism where a genetic change is both good and bad (Dyson, 2019).

While the first case of SCD was reported by James B. Herrick, a cardiologist, in 1910, who under a microscope observed the "peculiar elongated and sickle-shaped" red blood cells of a dental student from Grenada, recorded cases have been traced back to pre-dynastic Egypt (3,200 BCE), with further cases in classical Roman times (circa 450 CE). SCD has also been long known of in Africa, with Ballas (2015) observing that African tribal names for SCD are characterised by the alliteration of consonants and assonance of vowels that resemble the experience of sickle pain, such as *Chwechweechwe* (Ga tribe), possibly meaning "relentless, perpetual chewing", and *HemKom* (Adangme tribe), meaning "body-biting". In the USA, the term "sickle cell anemia" was introduced by Vernon Mason in 1922, and the term "sickle cell disease" by Julius Bauer in 1940. Linus Pauling ushered in an understanding that a single change at the molecular level produces the altered form of haemoglobin responsible for SCD (Pauling et al., 1949).

1.3 Prevalence of SCD

SCD affects millions of people worldwide with an annual incidence estimated at between 275,000 - 300,000 births per year globally (Modell & Darlison, 2008), with numbers expected to rise by more than 25% to 400,000 individuals annually by 2050 (Piel 2013). More than 85% of cases occur in sub-Saharan Africa, with other global hotspots being North-East Africa, the Caribbean, Central and South America, parts of India, the Middle East and Mediterranean countries (Colombatti et al., 2022). Within these regions the HbS gene frequency ranges from 10%-30%. In the United States, an estimated 100,000 Americans are affected, with an average incidence of 1 out of every 365 Black or African-American births (Cimpeanu et al., 2021). In England, SCD affects about 1 in 2000 live births and there are currently estimated to be approximately 12,500 to 14,000 people in the UK living with SCD, making it the most common single gene disorder, predominantly affecting people with African or Caribbean heritage (WMQRS, 2016, Dormandy 2017).

SCD used to be a seen as a disease of childhood because few individuals survived into adulthood (Chaturvedi & DeBaun, 2016), but since the introduction of treatments such as

hydroxycarbamide or regular blood transfusions, a number of cohort studies have demonstrated that in high-income and middle-income countries life expectancy has risen significantly since the 1970s. Those in high-income countries such as the US and UK regularly live into their mid-sixties (Chaturvedi & DeBaun, 2016; Kato et al., 2018), though this is still around 20 years less than those without SCD (Gardner et al., 2016). This contrasts sharply with data available about high mortality rates in low-resource settings, including Africa and India (Colombatti et al, 2022). For example, data from African studies indicate mortality rates for children below five years of age as being 50–90%, with most of these dying from infections, including malaria (Grosse et al., 2011).

1.4 The psychological impact of living with SCD

The impact of SCD upon the affected person's life is often significant. For example, a large-scale American prospective epidemiological survey (McClish et al., 2005) found on average, people with SCD reported severely compromised Health Related Quality of Life (HRQoL) in comparison to the general population and people with other chronic conditions such as cystic fibrosis and asthma. Another study found a sample of 96 adults with SCD had HRQoL that was significantly lower than that of the UK general population (Anie et al., 2002). People with SCD also experience a heightened prevalence of psychological distress compared to general population estimates, with clinical rates of depression ranging between 28-35% and for anxiety 6-14% (Levenson et al., 2008; Adam et al., 2017; Pecker & Darbari, 2019). This is important as when SCD patients have co-morbid mental health problems, this predicts poorer quality of life, greater disability, increased rates of hospital admissions, poorer treatment adherence and poorer health outcomes (Aljuburi, et al., 2013; Adam et al., 2017). It is also a better predictor of functioning than medical variables. For example, depression and anxiety have been shown to be larger predictors of pain factors than disease phenotype, and result in increased frequency, intensity, distress and disruption due to pain (Levenson et al., 2008).

Such interactions between mental and physical health are common in a range of long-term health conditions (Naylor et al., 2016). In addition to the obvious challenges of living with the unpredictable symptoms of SCD such as pain, fatigue, and other complications, higher rates of psychological distress can be attributed to numerous biopsychosocial causes. People often have episodes of ill health and need to attend or stay in hospital regularly for treatment, which can have far-reaching consequences upon all areas of their lives, such as schooling and education, work, relationships with family and friends, and leisure activities (Midence et al.,

1993; Sickle Cell Society, 2019). In childhood and adolescence, each developmental phase can be impacted (Telfair, 1994), and episodes of sickle cell painful crisis requiring hospitalisation can be life threatening, or perceived to be so, resulting in post-traumatic stress reactions (Hofmann et al., 2007).

1.5 Health and race related stigma and discrimination

Experiences of health-related stigma (Weiss et al., 2006) are commonly reported by people with SCD, often associated with their need to use opioids and frequent visits to emergency departments. Goffman (1963) defined a stigma as "an attribute that is deeply discrediting", which sadly is often the case with having SCD. Ballas (2015) lists some of the labels applied to people with SCD, such as 'sickler', 'frequent flyer', 'drug seeker', and 'malingerer'. In their meta-analysis of 27 studies of stigma in SCD (all US based), Bulgin et al. (2018) identified four stigma-related domains that are relevant to and potentially harmful for patients with SCD:

(1) The negative social consequences of stigma from family, friends and the general public, which results in concerns about disclosing their SCD status for fear of being treated differently or discriminated against.
(2) The negative effect of stigma on psychological well-being, leading to experiences such as internalized stigma, social isolation, anxiety, shame and guilt, depressive symptomatology, stress and anger (see also Holloway et al., 2017).
(3) The negative effect of stigma on physiological well-being, with those reporting higher rates of disease and race-based discrimination delaying care seeking and experiencing greater pain severity, burden and interference.
(4) The impact of stigma on patient-provider relationship and care-seeking behaviours, with those who have experienced more discrimination likely to be non-adherent to medical recommendations and more mistrusting.

Particularly concerning are the findings that both disease and race-based discrimination are frequently reported as being experienced from health care providers. Several US studies have highlighted common experiences of being stigmatised as drug seekers during hospital care, and having their pain discredited (Haywood et al., 2013; 2014; Wakefield et al., 2018). In England, an All-Party Parliamentary Group inquiry report entitled 'No One's Listening' was published in November 2021 (Sickle Cell Society, 2021). This report found "serious care failings" in acute services for people with SCD and evidence of deep racial inequality in the healthcare system. This brought into sharp focus the lack of understanding of SCD and the

battles people with this condition face, and concluded that a weight of the evidence suggests that the negative attitudes towards people with SCD are often underpinned by racism.

Previous studies appear to support this, particularly in relation to opioid usage. One US survey showed that over half of emergency department doctors and nearly a quarter of haematologists believed that one in five of SCD patients were 'addicted' to analgesics (Shapiro et al., 1997). In another US survey, 63% of nurses believed that 'drug addiction frequently develops' among SCD patients (Pack-Mabien et al., 2001). Such attitudes are unfounded as it appears the majority of people with SCD manage their pain at home and are reluctant to attend hospital unless the pain is unbearable (Smith et al., 2008)

1.6 Access to psychological support

In light of the above factors, the importance of access to psychology is argued for strongly in key policy documents (Sickle Cell Society, 2018). A systematic Cochrane review by Anie and Green (2015) sought to examine the evidence for psychological interventions that aimed to improve the ability of people with SCD to cope with their condition, and included seven eligible studies. Two of these interventions focused on education about SCD (Boroffice, 1991; Kaslow, 2000). Four were Cognitive Behaviour Therapy (CBT) based, with two taking the form of individual therapy (Gil, 1996; Gil, 1997), and two being group-based (Thomas, 1999; Broome, 2001). The remaining study was home-based therapy for adolescents with family members, and included patient education and CBT elements (Barakat, 2010). Five of these studies, with 260 people, had suitable data which they entered into the statistical analysis.

Anie and Green (2015) concluded that interventions which focused on education about SCD were effective in improving knowledge and attitudes about the condition, while CBT may be helpful for people with SCD, but its effectiveness remains unclear because of the poor quality of the studies. One of these studies showed that CBT reduced the affective reactions to pain, though not the intensity of the pain (Thomas, 1999). None of the CBT studies reported on changes in mood as an outcome. A subsequent literature review of non-pharmacological approaches for pain by Williams and Tanabe (2016) including 28 studies, found the strongest supporting evidence was for interventions involving CBT. In the nine CBT studies included, participants reported improvements in pain, but this was only statistically significant in three of them.

Despite the fact the evidence for the efficacy of psychological therapies in SCD is so limited, there are numerous studies and reviews indicating the effectiveness of psychological therapies such as CBT and Acceptance and Commitment Therapy (ACT) in addressing

problems relevant to people with SCD, such as chronic pain and fatigue (Adamson et al., 2020; Williams et al., 2020; McCracken et al., 2022). Unfortunately, there are barriers to people with SCD accessing such psychological therapies. It is recommended that specialist multidisciplinary haemoglobinopathy teams should include clinical/health or counselling psychologists (Sickle Cell Society, 2018), but the Peer Review Programme 2014-16 Overview Report (WMQRS, 2016) highlighted concerns about poor access to psychology services in 65% of the services reviewed, and many services lacked dedicated support from psychologists with specialist expertise in haemoglobin disorders. Where psychological support was available, the amount of time allocated was usually insufficient for the number of patients.

There are various intersecting reasons why people with SCD are also less likely to access mainstream psychology services, such as Improving Access to Psychological Therapies (IAPT) services. As previously mentioned, people with SCD in England are almost exclusively black (Dormandy, 2017), and therefore from a group who are under-represented in IAPT services (NHS Race and Health Observatory, 2023). Mistrust of statutory mental health services and concerns about the additional stigma of being labelled as having a mental health condition are likely to be important barriers (Project, 2023). Many psychology services embedded within Haematology departments seek to overcome such barriers by attempting to normalise psychology as a routine part of care (Thomas et al., 2009). Difficulties regularly attending appointments due to episodes of ill health also can result in people with SCD being discharged from IAPT services due to their traditionally strict cancellation and 'did not attend' policies.

The Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms (NHS England, 2018) and IAPT Black, Asian and Minority Ethnic (BAME) Positive Practice Guidance (Beck et al., 2019) are two recent documents of relevance which could result in people with SCD more frequently accessing IAPT services. The issue of ensuring people with SCD have access to appropriately tailored psychological therapies has clear relevance to the profession of Counselling Psychology. Its commitment to promoting empowerment and social justice, and the recognition of the role social contexts, oppression and discrimination have on psychological distress, are all highlighted as being important considerations in relation to people with SCD in the 'No One's Listening' report (Sickle Cell Society, 2021).

CHAPTER 2: CRITICAL LITERATURE REVIEW

"Of all the forms of inequality, injustice in health is the most shocking and inhuman"

Attributed to Martin Luther King, Jr.

2.1 Background

Whilst the Covid-19 pandemic has drawn attention to healthcare disparities and the way in which some groups, such as BAME communities and those living in deprived areas, were disproportionately affected by the virus (Office for National Statistics, 2020), such disparities have existed for decades, particularly in relation to people with SCD. For example, in England SCD patients admitted to hospital from the most deprived areas are twice as likely to die in hospital in comparison with those admitted from the least deprived areas (Aljuburi et al., 2013). Also in England, while Cystic Fibrosis affects around 10,000 people compared with 12-15,000 with SCD, it attracts more than 30 times more financial support for clinical care and services (Dyson & Atkin, 2013). The 'No One's Listening' report raised serious concerns about the insufficient investment in sickle cell care over the years. The fact SCD mostly affects black people has been cited as one of the reasons for this health inequality, with some authors arguing this is a clear example of structural racism (Power-Hays & McGann, 2020). This disparity has had an impact upon the lack of research funding and slow development of new disease modifying treatments for SCD in the US, UK and worldwide (Strouse et al., 2013; Lee et al., 2019; Farooq et al., 2020; Sickle Cell Society, 2021).

2.2 Haematopoietic Stem Cell Transplantation (HSCT)

At present, Haematopoietic Stem Cell Transplantation (HSCT) is the only cure for SCD. Haematopoietic stem cells are blood-forming cells, and the aim of an allogeneic HSCT is to replace a recipient's stem cells with those from a donor so that their bone marrow starts producing the same normal red blood cells. The donated stem cells need to carry a special genetic marker known as a human leukocyte antigen (HLA), which is identical or very similar to that of the recipient of the transplant, and the chances of getting a match is highest from a sibling or another close family member. An allogeneic HSCT can be contrasted with an autologous transplant, which is where the person's own stem cells are collected and are put back into their bloodstream after they are altered by viral integration or genome editing, though such approaches are still in the experimental phase in relation to SCD (Bauer et al., 2017). Since its first successful use in 1957, HSCT has been utilized for several decades for

the treatment and cure of haematological malignancies including lymphoma, myeloma, and leukaemia, and for immune diseases such as multiple sclerosis (Bazinet & Popradi, 2019).

The first HSCT conducted for SCD was performed in 1984 in the United States on an 8-year-old girl who had also developed acute myeloid leukaemia. Her leukaemia was cured and she was converted to sickle cell trait (Johnson et al., 1984). Despite this success, it is estimated that since then less than 3000 people with SCD have undergone this procedure throughout the world, with SCD-free survival being reported as over 85% (Cimpeanu et al., 2021). Around 85% of HSCT recipients have been children (Gluckman et al., 2017). In the past it was not considered an option for adults with SCD due to concerns that because of the organ damage caused by SCD over time, older patients would not tolerate the intensive toxicity of myeloablative conditioning (chemotherapy and radiation therapy) that is required to clear space in their bone marrows for the new stem cells (Hsieh et al., 2009). With increasing age there is also a greater risk of graft-versus-host disease (GVHD), where the new stem cells start to attack other cells in the recipient's body (Khemani et al., 2019).

Encouragingly, recent clinical studies have demonstrated good results of matched sibling allogeneic HSCT with reduced intensity or nonmyeloablative conditioning for adults with SCD (Cimpeanu et al., 2021; Alzahrani et al., 2021), which currently is made up of an immunosuppressive drug and low dose radiotherapy. Because the reduced intensity conditioning the recipient undergoes is not strong enough to remove all their own blood stem cells, after HSCT they will have a mix of blood cells from their own and from the donor's stem cells. This is called stable mixed chimerism. Abraham et al. (2017) concluded that greater than 25% of peripheral blood cells need to be of donor stem cell origin for the resolution of SCD-related symptoms. If the chimerism level is consistently low or drops, there is a risk of graft failure and the recurrence of SCD (see Appendix 1 for an overview of the transplantation process in SCD).

A systematic review by Badawy et al. (2021) sought to explore the effects of HSCT on Health-related Quality of Life (HRQOL), which focuses on the impact of a person's health on their ability to live a fulfilling life (World Health Organization, 1995). This review included a total of seven studies, all USA based, involving 101 participants with SCD. Most studies reported improvements in HRQOL following HSCT, with four studies finding significant improvements in the physical, emotional, psychosocial, general health, bodily pain, pain interference, and vitality domains (Kelly et al., 2012, Bhatia et al., 2015; Krishnamurti et al., 2019; Saraf et al., 2016). However, Badawy et al. call for more longitudinal studies to assess the sustainability of these effects.

As of 2020, HSCT has been funded for adults with SCD by NHS England, though it is currently only available for patients with a matched sibling and severe SCD with complications, where the potential benefits of the procedure outweigh the risks (NHS England, 2019a). It is estimated only 18% of potential candidates will have an HLA matched donor (Chaturvedi & DeBaun, 2016), but the evidence is not yet strong enough for haploidentical HSCT, where the donor is a half-matched family member. Currently this type of donation is not funded by the NHS and is performed only as part of research studies, such as the recently launched REDRESS (RElated Haplo-DonoR Haematopoietic stEm Cell Transplantation for Adults with Severe Sickle Cell Disease) randomised trial (https://www.redresstrial.co.uk). If showing clear benefit, this could lead to NHS funding of this type of transplant as well. Regardless of this, the number of people with SCD in England undergoing HSCT is expected to increase significantly in the coming years.

2.3 Psychological support needs during and after HSCT

The provision of psychology support is deemed important for patients undergoing HSCT, as studies of those having them predominantly to cure blood cancers have reported a high prevalence of psychological distress (Amonoo et al., 2019). This is particularly true during hospitalisation, with studies reporting up to 25% of patients meet clinical criteria for depression and/or an anxiety disorder (Baliousis et al., 2016). Following transplantation, psychological distress generally improves but can persist with up to 40% of patients experiencing depression and up to 30% experiencing anxiety even a year afterwards (Mosher et al., 2009). Suicidal ideation and increased rates of death by suicide have been reported in patients with cancer who have undergone HSCT (Tichelli et al., 2013), while the prevalence of post-traumatic stress disorder (PTSD) was found to be 20% in one study (Hefner et al., 2014). However, it is difficult to ascertain the extent to which these findings are associated with a cancer diagnosis and treatment, versus features of the actual HSCT itself. Psychological distress can negatively impact recovery, function, and health outcomes, including mortality and a higher risk of GVHD (Amonoo et al. 2019).

In light of this, at most transplant centres patients undergo some form of psychological evaluation, primarily to identify risk factors and prepare them for the treatment to come (Yalvaç et al., 2016; Lagerdahl et al., 2024), while close monitoring is advised for emerging psychosocial issues following the transplant process (Datta et al., 2020). Despite the recognition of the importance of taking psychosocial contexts into consideration, a national survey of UK transplant centres by Naidoo et al. (2022) found that the availability of psychological care to HSCT recipients throughout the UK is markedly varied, with many

healthcare providers considering it insufficient to meet patients' needs. They go onto report that only 29% of those with a non-malignant condition, which would include people with SCD, could access psychological services in haemato-oncology, and instead had to be referred out of service.

In terms of psychological interventions which seek to alleviate psychological distress in HSCT recipients, a systematic review with meta-analysis by Baliousis et al. (2016) included eleven articles for nine interventions which met the inclusion criteria. Five interventions involved a substantial psychotherapy component with the remainder being less specialist (e.g. psychoeducation with relaxation, task instructions). Seven interventions incorporated CBT methods, including different forms of delivery, such as via telephone sessions to try to reduce PTSD symptoms related to the treatment (DuHamel et al., 2010). Baliousis et al. concluded that the results suggested a potential, albeit small, benefit of psychological interventions for distress in HSCT. This was particularly the case for those with a substantial interventionist input, incorporating a major psychological component such as CBT or emotional processing, which tended to show better efficacy than those with less psychological or more self-directed focus. They caution that such conclusions remain tentative, however, in light of a range of methodological limitations in a number of the studies and threats to internal validity such as a high risk of bias, and possible publication bias.

An integrative literature review of HSCTs for haematologic malignancies conducted by Adelstein et al. (2014) sought to determine whether meaning-making might be helpful to improve coping and psychological adaptation as patients navigate HSCT. This included 24 studies published between 1989 and 2012. They concluded that the studies revealed meaning-making was an important part of effective coping, and that those patients who found meaning in their experience of HSCT were better able to manage their physical symptoms, and were less likely to report psychological morbidity than those who struggled to find meaning in their experience. They concluded their review by recommending that interventions designed to promote meaning-making would be beneficial to patients undergoing a HSCT.

None of the studies or reviews mentioned so far included people with SCD who have undergone HSCT, and so it is even less clear what the psychological needs of this group are, given their uniqueness as compared to the majority of people who have had them to cure haematologic malignancies where a stem cell transplant can be their last chance of survival. While overall improvements in HRQOL measures are reported, those with long-term complications caused by SCD, such as organ damage and chronic pain conditions, continue

to be impacted in terms of their physical functioning (Badawy et al., 2021). Of particular note, a recent retrospective chart review found six people with SCD (42.9% of those reviewed) reported suicidal ideation and one a suicide attempt within a year of a successful HSCT, all of whom had a previous history of depression, suicidal ideation, or both (Mishkin et al., 2022). The authors question whether patients are sufficiently emotionally prepared for the post-HSCT year, during which time pain and depression are likely to continue.

2.4 Literature search

I sought to carry out a systematic literature search to discover: 'What is currently known about the lived experience of HSCT for people with SCD?' I reasoned that gaining an in-depth understanding of such experiences could better equip psychological therapists in providing support to them. The approach I took to my literature search conformed to the recommendations from the Preferred Reporting Items for Systematic Reviews (PRISMA) guidelines (Page et al., 2021). The scope of the literature search was kept narrow in order to focus only upon studies that could reveal insights into what the actual experience of HSCT is like from a first-person perspective.

2.4.1 Inclusion criteria

- People with Sickle Cell Disease who have undergone HSCT.
- Qualitative or mixed study design that included qualitative components and examined experiences.
- Studies including recipients aged 13 years plus (studies with children were included if they also included adolescents and/or adults).
- In peer reviewed journals.

2.4.2 Exclusion criteria

- Quantitative study designs, such as those focused on quality of life where this is only based on completion of a self-report measure at a set point in time.
- If the study primarily focused on medical outcomes (including pain and opioid use), attitudes towards transplants, or neurocognitive function after transplant.
- Studies that primarily focused upon the donor's experience.
- Unpublished dissertations or information from the grey literature.

2.4.3 Search terms and selection criteria

Following a number of scoping searches to explore publications and the terminology used, I undertook a systematic search in May 2024. Three electronic databases were searched,

these being PsycINFO (EBSCOhost), CINAHL (EBSCOhost), and PubMed (NCBI). I set a start date of 1984 to identify any accounts available since the first HSCT was carried out for SCD. I decided to only include studies where recipients were 13-years old or above, as I reasoned they would have reached a stage of cognitive development where they would be able to reflect upon and report their own experiences. A range of possible combinations of key words were employed, following the PICOS framework (Methley et al., 2014).

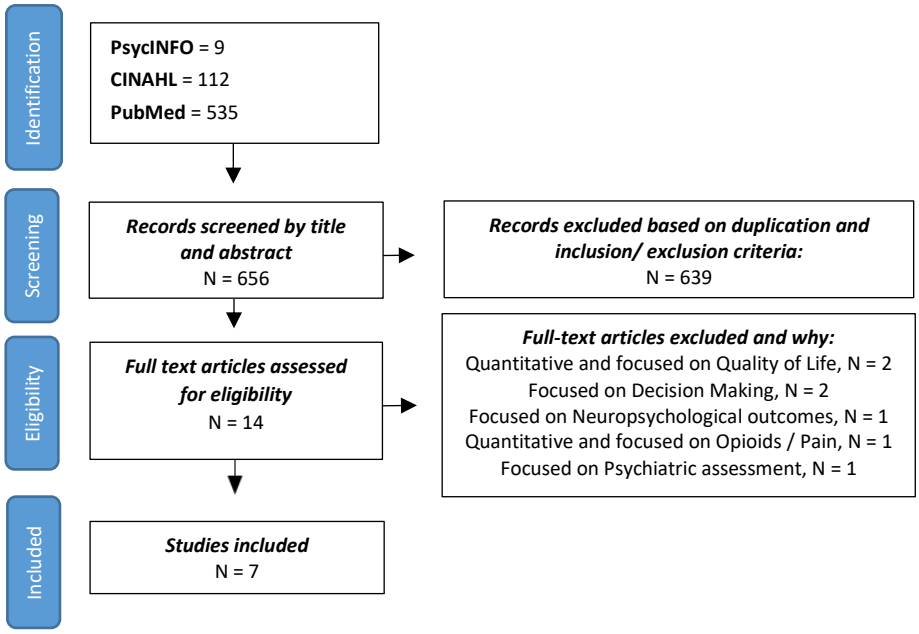
Table 1: Search terms used

1. TI/AB “Sickle cell” OR “Sickle cell disease” OR “sickle cell anaemia” OR “sickle cell anemia”
2. TI/AB 1# AND “Haematopoietic stem cell transplant” OR “stem cell” OR transplant* OR “bone marrow” OR HSCT
3. TI/AB 2# AND Experience OR Psych* OR “quality of life”
4. TI/AB 3# AND Qualitative OR Interview* OR “case stud*” OR “mixed method*”
5. TI/AB 4# OR MeSH terms of "Anemia, Sickle Cell" AND "Hematopoietic Stem Cell Transplantation" for PubMed and CINAHL
6. TI/AB 4# OR subject terms (DE) of "Sickle Cell Disease" AND "Stem Cells" for PsycINFO

2.4.4 Data extraction and management

A PRISMA flow diagram giving details of how studies were selected to include in this review is provided in Figure 1. The literature search produced 656 articles in total (Appendix 2). I carried out a filtering analysis based on the inclusion and exclusion criteria by reading the titles and abstracts of each study, and removed duplicates. The full text of 14 articles were assessed for eligibility, and a further seven were excluded, leaving seven eligible studies published between 2018 to 2023.

Figure 1: PRISMA flow diagram



2.5 Results

Key details of the seven studies included are presented in Appendix 3, while Table 2 provides a summary of the demographics. Five of the studies were USA based, one Canadian, and one from The Netherlands. The studies by Gallo et al. (2019a), Gallo et al. (2019b) and Hastings et al. (2019) were all linked to the University of Illinois at Chicago and featured two of the same researchers in all three studies (Agatha Gallo and Crystal Patil). The total number of participants involved across all the studies would appear to be 65 in total. The study by Gallo et al. (2019b) included the perspectives of both recipients and donors, though for the purposes of this summary I focused exclusively on the accounts given by the recipients. Of the estimated 65 participants, seven transplants were reported to have been unsuccessful across four of the studies.

In terms of ages, in the study by Khemani et al. (2018) some recipients interviewed were aged 16 and 17 at the time of their HSCT, though it was not reported how many were these ages and the range was from 5 to 20 years old, with a mean age of 10.8. Ages in the other six studies ranged from 13 years old in the study by Bruce et al. (2022), up to the age of 52 years old in the studies by Gallo et al. (2019a) and Gallo et al. (2019b).

Table 2. Demographics of included studies	
Estimated total number of HSCT recipients	65
Number with failed transplants	7
Age range	5 to 52 years old
Estimated total number of females	28

The seven studies all adopted qualitative methodologies, with three of these being included within a mixed methods approach (Gallo et al., 2019a; Hastings et al., 2019; Dovern et al., 2023) and one within a case study approach (Bruce et al., 2022). I have included brief details of the quantitative components of these studies in Appendix 3, where they reported improvements in Health-related Quality of Life (HRQOL) after HSCT. The studies by Gallo et al. (2019a), Gallo et al. (2019b) and Hastings et al. (2019) all employed content analysis. The exact methodology used in the study by Hastings et al. (2019) is a little hard to make out, with the design being given as a descriptive case-study approach and a reference made to the case study work of Robert Stake (2005). The studies by Khemani et al. (2018), Abu al Hamayel et al. (2021) and Dovern et al. (2023), all adopted thematic analysis. Finally, in the study by Bruce et al. (2022), a multiple case study methodology was adopted, utilising multiple sources of evidence including QoL inventories, interviews and medical records analysis.

2.6 Quality assessment of the included studies

In order to judge the methodological quality of the qualitative aspect of these studies, I used the Critical Appraisal Skills Programme (CASP) qualitative checklist tool (Critical Appraisal Skills Programme, 2018). Long et al. (2020) discuss the use of the tool in quality appraisals and added 'somewhat' as a fourth response option to give a greater degree of nuance, and also a question to consider the underlying theoretical, ontological and epistemological framework of each study reviewed. I have included both of these questions.

As illustrated in Appendix 4, in terms of each CASP question I gave most of the studies a 'Yes' response. Given the limited number of people with SCD having undergone HSCT, the sample sizes were all understandably small and the recruitment strategies adopted were all reasonable and appropriate. There were common observations made across all seven studies. One such finding was that none of them were clear about their theoretical underpinnings, so it was difficult to conclude how consistent and conceptually coherent they were and whether this quality issue was due to problems with methodology or reporting. For example, the studies that adopted thematic analysis (Khemani et al., 2018; Abu al Hamayel et al., 2021; Dovern et al., 2023) all cited Braun & Clarke (2006). Thematic analysis methods can be applied across a range of theoretical and epistemological approaches (Clarke et al., 2015), however, but none of these three studies explicitly reported which they adopted and the reader has to infer this from the write up, which seems closest to a direct realist position focused on description and manifest meanings (Willig, 2021). In the study by Bruce et al. (2022) a reference is given to the case study approach of Robert Yin (2009), who discusses the importance of developing a theory in the design phase of a study, but Bruce et al. do not discuss this or their epistemological orientation.

There were also minimal reflections on the researchers' preunderstandings or how this may have shaped their data analysis in any of the studies, and none included sections on researcher reflexivity or discussions of this, which Stainton-Rogers and Willig (2017) argue is an essential element of qualitative research, as meaning and themes do not 'emerge' from the data, but rather researchers are actively engaged in the process of meaning-making. Finally, ethical considerations were only briefly touched upon by the seven studies, and mostly in relation to the way in which they sought informed consent, conducted the interviews and maintained confidentiality. Larger ethical considerations about the benefits and risks of participation in the studies were not discussed.

2.7 Reflexive evaluation of the systematic literature search

In choosing to undertake a systematic literature search, I was conscious of deliberately going beyond the less structured approach adopted in the many Counselling Psychology doctoral theses I had read. These tended to include limited details of the methods by which the literature they cited were obtained. In contrast, I sought to conduct a literature search that could be repeated by other researchers to identify any new studies that could emerge in the coming years. I was also keen to make the most of the opportunity to acquire these research skills with the support of tutorials from the University's subject librarian. This was an exceptionally steep learning curve as I became practiced in searching different databases, combining various keywords with MeSH and subject headings, using Boolean operators, and applying search filters. At the time, my decision to not include grey literature in my systematic search was influenced by the following key factors:

1. I had undertaken numerous scoping searches using multiple search engines and databases, including EThOS to identify any unpublished UK doctoral theses investigating this topic. Despite using similar search terms as those I used during my systematic search, I had not identified any additional studies of relevance.
2. I thought that because grey literature has usually not been subjected to the same level of peer review and rigorous scrutiny by experts as published material, it may not have the same reliability and quality (Benzies et al., 2006; Hopewell et al., 2007). This was something of a misconception however, as I now know some forms of grey literature such as theses and dissertations can be of a very high quality and be rigorously reviewed (Bellefontaine et al., 2014).
3. Systematic reviews aim to generate answers to focused research questions (Paez, 2017). I reasoned that many forms of grey literature such as ongoing research reported in conference abstracts, would not give me access to enough detailed material to evaluate and include in a synthesis to answer my question of *'What is currently known about the lived experience of HSCT for people with SCD?'*

Another contributing factor was my lack of knowledge of the best method for conducting a rigorous search of the grey literature, which had not formed part of the teaching on the doctorate. Grey literature is very heterogenous and scattered across various places, requiring the use of multiple search engines and being potentially very time-consuming to identify and evaluate (Benzies et al., 2006; Saleh et al., 2014). As a lone researcher rather than a member of a research team, I was conscious of the tight deadline I had in which to complete my thesis and all the other parts of the research process I had to acquire competence in and complete. While Universities do usually provide guidance for searching

grey literature, there was a degree of pragmatism involved in concluding I had done a comprehensive enough search to not miss any studies accessible within the commercially published literature or any UK-based research doctoral theses.

Since completing my thesis I have become more aware of the benefits of including grey literature in a systematic search, for example in identifying emerging research and preprints. These may be more recent than formally published research literature, which can take time to pass through the lengthy peer review and editorial process. I also acknowledge that grey literature can potentially help in overcoming the publication bias for studies that find 'positive' or 'interesting' results, by also seeking to include unpublished research findings with neutral or negative results to produce a more balanced understanding of the topic (Paez, 2017; Lefebvre et al., 2024). Such benefits have caused me to rethink my rationale for excluding grey literature from my systematic search.

While I am still confident that by searching EThOS I did not miss any relevant UK dissertations, I cannot say the same about dissertations from other countries, though my search would have caught them if they had gone on to be published. If I were to repeat my systematic search, I would now consider including databases such as EThOS, OATD, NDLTD, or WorldCat, to access graduate theses and dissertations published around the world. While using the same combinations of key words, I would impose some additional constraints on the scope of the search, such as only including English-language or translated research from which I would be able to extract details of the experience of HSCT for SCD. I would then apply the CASP qualitative checklist tool (Critical Appraisal Skills Programme, 2018) to evaluate the quality, reliability, and validity of these studies. However, I would still seek to achieve a reasonably high degree of consistency and homogeneity in the type of grey literature included, and ensure it had been subjected to at least a moderate level of scrutiny before judging if it could be included in a synthesis. By including such selected grey literature in a future systematic search, I believe it would be more inclusive and comprehensive, while still being reproducible.

2.8 Synthesis of studies

Through a process of carefully reading and rereading each study, and thoroughly familiarising myself with them, I sought to analyse and interpret their findings. In doing so I referred to the steps carried out when conducting a meta-synthesis (Willig, 2021; 191) and was also guided by Thomas and Harden's (2008) thematic synthesis approach. This resulted in the construction of seven major themes, detailed below:

1. Deciding to have the transplant

Two studies explicitly explored the process of deciding to proceed with HSCT. In the study by Khemani et al. (2018), participants reported the burden of SCD and progression of disease-related complications were the strongest factors in deciding to have a HSCT, though acknowledged having concerns about the side effects, social isolation, and possibility it might not be successful. In the study by Gallo et al. (2019b), recipients also cited the worsening of complications over time and increased episodes of pain due to SCD as major motivating factors, with HSCT being seen as a "cure" and chance to live a longer, healthier life.

Further factors that were important in proceeding with the transplant in the Khemani et al. (2018) study, were having a strong familial support system, as well as the availability of a sibling donor, which led some to conclude it was "meant to be" and a "perfect sign". In the study by Gallo et al. (2019b), recipients' spoke of the influence and at times pressure to go ahead with the transplant from family and health providers. The recipients whose transplants had failed in the Gallo et al. (2019a) and Gallo et al. (2019b) studies spoke of having had reservations and not feeling they had sufficient time to consider their decision but decided to go ahead with it due to the possibility of being cured of sickle cell. They also felt obligated to have the transplant so as not to disappoint family, friends and providers who had encouraged them to do so.

2. Physical and psychological challenges during and following the transplant

In the studies by Khemani et al. (2018), Gallo et al. (2019a), Bruce et al. (2022), and Dovern et al. (2023), the process of HSCT was described as long and arduous, which for some was anxiety provoking because of the side effects of the conditioning regime such as headaches, fever, weight and hair loss, nausea and vomiting. Those in the Bruce et al. study spoke of fears the transplant would fail, while in the Gallo et al. (2019b) study, many spoke of being unprepared for the side effects they experienced, which were worse than expected. In the Hastings et al. (2019) study, recipients also reported side effects and complications that they weren't expecting. Some said while knowing about them wouldn't have led them to change their minds about proceeding with the transplant, it could have allowed them to feel more mentally prepared. In the Abu al Hamayel et al. (2021) study, participants reported HSCT-related pain that started during or immediately after commencing chemotherapy. Those who had experienced severe and frequent painful crises prior to HSCT tended to describe this as manageable, compared to those with fewer crises who found the pain more intense, saying it was "like death" and "traumatic."

In each of the studies by Khemani et al. (2018), Gallo et al. (2019b), Bruce et al. (2022), and Dovern et al. (2023), the long recovery period was described as being psychologically difficult and socially isolating due to the need to restrict social activities to avoid infections. Most participants in the Gallo et al. (2019b) study reported the month they spent in hospital as being long, tedious and boring. In the study by Dovern et al. (2023), emotional struggles were common, with recipients expressing the need for psychological help and guidance, which was lacking. Finally, in the Gallo et al. (2019b) study, the two recipients whose transplants failed lamented about being unprepared for the emotional toll the transplant would have on them, with one saying they had become deeply depressed and subsequently did not attend follow-up clinics.

3. Varying experiences with healthcare teams

Varying experiences with healthcare teams were reported in some of the studies. Participants in the Hastings et al. (2019) study described the transplant team as attentive and caring, feeling they'd done a great job of meeting their needs, while in the Gallo et al. (2019b) study, most recipients' relationships with the transplant team or haematology clinic staff were positive and trusting. One recipient, who was ambivalent and had expected a "cure" but continued to experience pain, felt confused by the lack of agreement among team members about the origin of her continued pain. Another recipient whose transplant had failed expressed disappointment about not receiving enough information about the length of time recovery would take. In the Abu al Hamayel et al. (2021) study, participants described insufficient agency in decisions about opioid use and weaning, with those who had support from healthcare providers having the most successful and positive experiences of weaning themselves off opioids.

4. The positive impact of the transplant despite some disappointments

The time between transplant and participant interviews varied from 1 year to 4.11 years in six of the studies, while surprisingly, in the Khemani et al. (2018) study, time since transplant ranged from 0 to 17 years. In this study participants spoke of discovering normalcy and a "new life" without the burden of SCD, with some referring to the day of the transplant as being their second birthday and continuing to celebrate it. In the Bruce et al. (2022) study, quality of life fluctuated over time, with it being unsatisfactory during the period recipients were hospitalised and the months after, but with clear improvements at one-year post HSCT. At this point, they described a crisis free life with positive psychological outcomes, feeling relieved they had truly overcome SCD and

reported being satisfied with life. Over time they gained social acceptance from their extended families and communities who had previously stigmatized and excluded them.

In most studies, participants described being pain free as one of the biggest benefits of the transplant, though it took up to two years for pain to resolve entirely post HSCT for recipients in the Abu al Hamayel et al. (2021) study. Despite this, a number of recipients did continue to experience pain due to avascular necrosis and other damage caused by SCD, which was disappointing to them (Gallo et al., 2019a; Dovern et al., 2023). In the study by Gallo et al. (2019a), recipients had refined definitions about the level of success or failure for the HSCT, with some saying full success would come when they could stop taking anti-rejection medication, and others recognising they may have to be on this for life. Most recipients in this study reframed the experience of HSCT to make it meaningful, even if they continued to experience chronic pain symptoms. None of the recipients in any of the studies expressed regrets about undergoing the transplant despite the disappointments and complications. This included the two whose transplants had failed in the Gallo et al. (2019b) study and the recipient whose transplant was not successful in the Hastings et al. (2019) study, who then chose to have a second one.

5. Psychological adjustment

In the Dovern et al. (2023) study, recipients struggled to emotionally process and adjust to not having SCD anymore, for example at first sticking to patterns of behaviour established from years of living with SCD, anticipating still getting sick and having a sickle cell crisis in certain situations, such as when getting cold and wet. At the time of the interview, recipients described the mental processing of having HSCT as taking longer than physical recovery, with some saying that only now did they feel ready to talk about their emotional struggles from the past. Recipients again expressed the need for psychological support.

6. New opportunities

In the studies by Khemani et al. (2018), Gallo et al. (2019a), Hastings et al. (2019) and Bruce et al. (2022), the recipients with successful HSCTs described welcoming and pursuing goals and opportunities in relation to their careers, education and leisure activities that would have not been possible whilst having SCD. This included taking up sports and other strenuous physical activities, with those in the Khemani et al. (2018) study expressing excitement at being given the opportunity for a “new life”. In the Abu al Hamayel et al. (2021) study, once their pain had reduced or resolved, participants also described being able to pursue activities such as re-enrolling in school, finding work, and

exercising regularly, with positive effects on their physical and mental health. Interestingly, while in the Dovern et al. (2023) study recipients spoke of the new opportunities open to them and a more physically and socially active life, at times they felt overwhelmed as they found themselves confronted with a new and unfamiliar reality that brought different challenges for which they needed time to adjust.

7. Altered views of the future

Participants in the Khemani et al. (2018) study described a sense of hope for the future, as did those with successful transplants in the Gallo et al. (2019b) study, who spoke of their optimism for living a longer life where they were able to do things they hadn't previously been able to do. Those in the Hastings et al. (2019) study described relief at not worrying anymore about future damage from SCD. Many recipients in the Dovern et al. (2023) study also reported optimism and plans for the future, such as to return to study, find new jobs, and start families, though some also reported a fear of SCD coming back, and some women had worries about the effect of HSCT on their fertility.

2.9 The relevance of meaning-making theoretical models

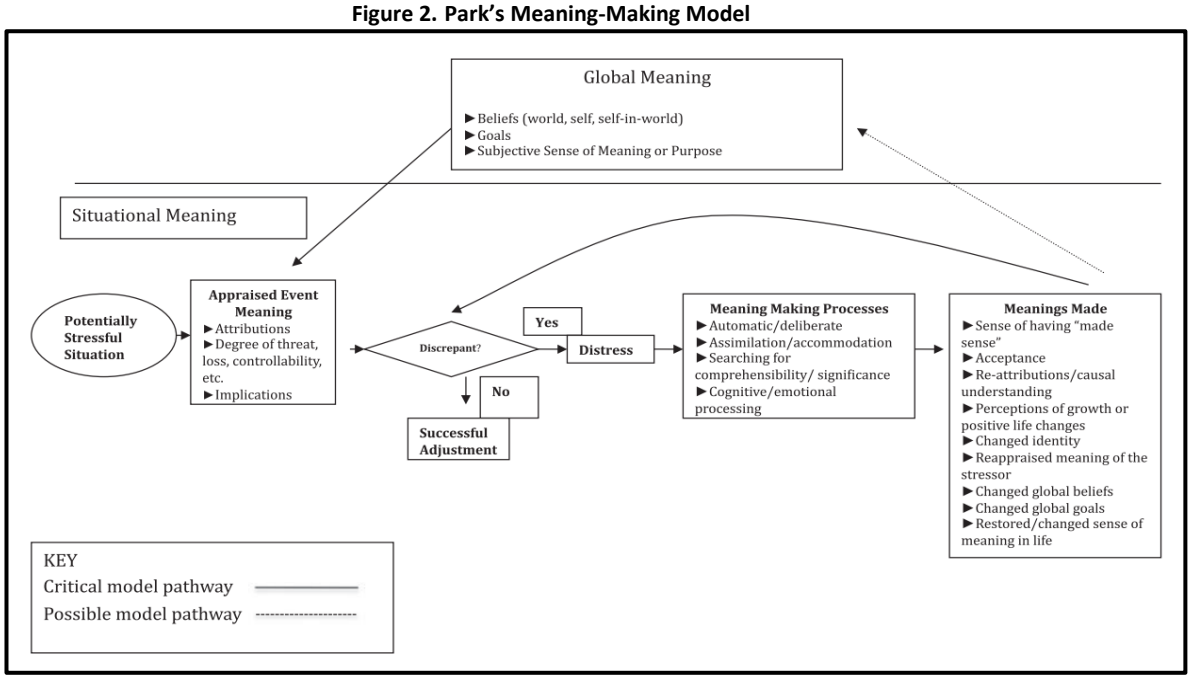
The study by Dovern et al. (2023) highlighted the psychological challenges of adjustment faced by HSCT recipients with SCD. Brennan (2001) defines adjustment as "the process of adaptation that occurs over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by changed circumstances in their lives". Meaning-making models, such as that presented by Crystal L. Park (2010), would appear to provide a useful interpretative framework for understanding the experience of HSCT and transitioning to a life without SCD. Park's model makes the following core assumptions:

A. People possess cognitive frameworks or core schemas, referred to as **global meaning**, through which they interpret their experiences of the world. These are socially constructed cognitive representations of the world, derived from the accumulation of life experiences and reflecting the person's social and cultural contexts.
B. If they experience a situation that challenges this global meaning, people will appraise this event and assign a **situational meaning** to it. If there is a discrepancy between situational and global meanings, this will evoke distress and disorientation, which people will use various coping strategies to try to alleviate, including initiating a process of **meaning-making**.

C. Better adjustment is achieved if the **meanings made** by the person succeed in reducing the discrepancy between appraised situational meanings and global meanings, and the experience is accommodated or assimilated into these previously held fundamental assumptions and meaning frameworks.

There are various versions of this model as applied to different life events, but a version of this is displayed in figure 2.

Figure 2. Park's Meaning-Making Model



Source: Park, 2010

Park's meaning-making model would predict that undergoing HSCT and adjusting to life without SCD would be a dynamic and cyclical process, requiring the reorganisation of global meanings, and the evaluation of prior coping responses. Such a process would be expected to take considerable time to complete, as would the emotional processing it requires, as was apparent in the accounts of the recipients in the Dovern et al. (2023) study.

In the studies of HSCT for SCD discrepancies existed for some recipients between their expectations and the actual experience of the transplant process, such as the length of time recovery took, its emotional toll, and the side effects and complications encountered (Gallo et al. 2019b; Hastings et al. 2019). Discrepancies also occurred between expectations and the outcome of the transplant, such as the continued experience of pain for some recipients (Gallo et al. 2019a; Dovern et al., 2023). Both these discrepancies would require recipients to make changes in situational meaning in order to adjust to the experiences they had. As we have also seen, participants in the Dovern et al. (2023) study struggled to emotionally process and adjust to not having SCD anymore. They felt overwhelmed as they found

themselves confronted with a new and unfamiliar reality that brought different challenges, which suggests changes were required at the global meanings level.

2.10 Rationale and aims of this study

The studies presented from the systematic literature search highlight the uniqueness of HSCT for SCD. Unlike other recipients with haematological malignancies whose health-related quality of life was likely to have been normal before their illness, people with SCD have never known a life without the impact of the disease. The study by Dovern et al. (2023) highlighted the psychological struggles experienced by recipients with SCD of HSCT and the need for support with this. In fact, in their discussion they argue that the ongoing psychological and social impact of SCD should not be underestimated, and that the mental repercussions and possible trauma from having had SCD should be addressed in the post-HSCT period. They suggest this would be most appropriately offered by psychologists with experience of working with SCD and HSCT recipients who can bring the required knowledge and skills to this work. The fact that two members of the research team are named as psychologists may have contributed to the greater richness of psychological material in this study.

I reasoned that further research adopting an explicitly psychological focus would be valuable to explore HSCT experiences in more detail and contribute to understanding how recipients can be supported psychologically through this major life transition. I also believed such a study would benefit from a Counselling Psychology perspective, with its focus on engaging with subjective and inter-subjective experiences and phenomenological ways of knowing, as well as the application of the humanistic values at Counselling Psychology's core toward enhancing growth and well-being. Furthermore, Counselling Psychology's avoidance of the medicalization of distress and emphasis on relational ways of '*being-with*' people during existential challenges appeared highly relevant to people undergoing HSCT (Woolfe, 1996; Orlans & Van Scoyoc, 2009; Cooper, 2009; Strawbridge & Woolfe, 2010).

There has been little published research investigating the applicability of Counselling Psychology principles to health settings generally, with none in relation to SCD, and no studies have taken place including SCD recipients who have undergone HSCT in England. In order to address these gaps, my research question was:

What is the lived experience of receiving Haematopoietic Stem Cell Transplantation (HSCT) in adults with sickle cell disease living in England?

CHAPTER 3: METHODOLOGY

3.1 Reflexivity on ontology and epistemology

McLeod (2001) writes that the ontological question asks what the form and nature of reality is, and, therefore, what is there that can be known about it? I ascribe to a critical realist position (Bhaskar, 1975; Pilgrim, 2020), which holds that reality exists independently of what we know or think about it (**Ontological realism**). We construe this reality in multiple ways, so knowledge generated about it is inevitably subjective, constructed by language, experience and other aspects of individuality, and will vary over time and place (**Epistemological relativism**). Critical realism appeals to me in steering a path between the realist certainties of the positivist paradigm and the radical relativism of more extreme forms of social constructionist and postmodern thought (Wilber, 2000; Willig, 2013).

In relation to SCD, I would argue strongly it exists as an ontologically real, mind-independent and intransitive inherited molecular biological entity. Dyson (2019) actually argues that SCD represents an important principle of critical realism, namely that things may be **actual** (be there) before they are **empirical** (observable and known by humans) and may be **real** (possessing mechanisms or causal powers) before they are actualized. As we have seen, SCD existed for many thousands of years but occurred largely in the absence of human knowledge about it until empirically observed under the microscope in the early twentieth century. The ways in which SCD has been construed and understood has varied over time and place, reflecting transient and socially constructed processes, and therefore being subject to epistemological relativism. The critical realist position of ontological realism together with epistemological relativism can also be applied to a HSCT. This is a major life event that entails making a real and powerful medical intervention upon a person's body which can cure them of the symptoms caused by the molecular entity known as SCD. The meanings people attribute to this event will, however, significantly shape their experiences of it.

Deciding upon the best way of working out what the experience of a HSCT is for the recipient is an exercise in **judgement rationality**, a further premise of critical realism (Pilgrim, 2020). This also entails answering the epistemological question 'What is the relationship between the knower and would-be knower and what can be known?' (Mcleod, 2001). As the type of knowledge I am seeking to generate is based upon the recipient's unique, subjective and intersubjective experience of the phenomenon that is a HSCT and how they make sense of this within a particular socio-historical context, I decided to adopt a hermeneutic phenomenological epistemology.

McLeod (2001) states that phenomenology and hermeneutics are the epistemological roots of all qualitative research undertaken in the tradition of Western human sciences. Edmund Husserl (1859-1938) was the founder of phenomenology as a philosophical movement, which aimed to describe the lived world of everyday experience as it appears in consciousness. This way of experiencing is shaped by each individual's unique cognitive and affective biases. Husserl developed a phenomenological method comprising a series of interrelated steps. This involves setting aside or 'bracketing' our 'natural attitude', the term he used to describe the network of assumptions and biases that we usually employ to make sense of our everyday world, in order to experience and describe phenomena as they appear to us in their essence, or in Husserl's famous directive, to return 'To the things themselves' (Spinelli, 2005; Langdridge, 2007; Finlay, 2011).

Martin Heidegger (1889-1976) was initially a student and assistant of Husserl but went on to question the possibility of being able to transcend ones' own experience of the world in order to identify the essence of a phenomenon. Heidegger insisted human existence must be interpreted and not simply described, claiming it was not possible to step outside of the historically and culturally situated nature of all our interpretations. Heidegger described his phenomenological approach to the study of human existence as 'hermeneutical' (Finlay, 2011). Hermeneutics has been defined as the theory, or 'art' of interpretation (Moran, 2000, Schmidt, 2006; Caputo, 2018). Hermeneutics has a long history, with its beginnings being associated with the interpretation of biblical texts, and its remit then extending to a much wider range of writings (Smith, 2007).

Hans-Georg Gadamer (1900-2002), who was a student of Heidegger, was also keen to stress the historically and culturally situated nature of all understanding. We need to recognise our pre-understandings and historicity, though we may only recognise them once the interpretation is underway (Smith et al., 2022). For Gadamer, a successful interpretation is always from a perspective, takes place from a position within history, requiring sensitivity to the use of language, and leading to alterations in the fore-understandings of the person making the interpretation. The famous 'hermeneutic circle' refers to the circularity that is inherent in the process of meaning-making, whereby parts can only be understood in light of an understanding of the whole, but that the whole can only be understood in light of an understanding of the parts (Schmidt, 2006; Willig, 2013).

A hermeneutic phenomenological epistemology would appear to fit well within a critical realist stance of epistemological relativism and ontological realism. For example, Hubert Dreyfus (1991; p253) described Heidegger as a 'minimal hermeneutic realist', a position

which recognises that what is real is not dependent on us and would have existed even if humans had not, but acknowledges the exact meaning and nature of reality is only made intelligible because we are here to ask such questions about it (Larkin et al., 2006).

3.2 Methodology and methods

3.2.1 Choosing a qualitative methodology

In terms of the selection of research methodology, I am heavily influenced by a pluralistic approach (Cooper & McLeod, 2007), a position increasingly adopted by Counselling Psychology in the UK (McAteer, 2010; Rafalin, 2010). Rescher (1993, p.79) defined pluralism as 'the doctrine that any substantial question admits of a variety of plausible but mutually conflicting responses'. This appeals to my predisposition for seeing things from different perspectives and honouring the partial truths each contain. At times in my life, I have thought it a problem that I have never been as certain as other people in my opinions and views on things, especially when they enter into a heated debate on a subject, whereas now I see it as a desirable quality and one very fitted to the practice of Counselling Psychology.

I fully endorse the view that there are numerous potentially appropriate ways to examine a particular topic of interest or phenomenon, and the choice of methodology and research design depends on the question posed (Hanley & Winter, 2016; Henton, 2016), with it even being possible to combine methodologies which subscribe to different epistemological positions (Willig, 2013). As I wished to understand the person's experience of HSCT and how they make sense of this in their own words and terms, I therefore proposed to approach this question through a qualitative analytic methodology, which is consistent with the hermeneutic phenomenological epistemology I have selected (Kasket, 2012) and a critical realist stance (Willig, 2016).

3.2.2 Interpretative Phenomenological Analysis (IPA)

In terms of specific qualitative analytic methodologies, given the very small number of adults who had received HSCT in England at the time of undertaking this study, it was clear the research question called for an idiographic approach, which is concerned with a focus on the particular and examining fewer participants at a greater depth (Reid et al., 2005; Smith et al., 2009), and follows in the tradition established by Gordon Willard Allport (1897-1967). Interpretative Phenomenological Analysis (IPA) is one such idiographic qualitative research methodology, concentrating as it does on detailed and intensive analysis of the accounts of

comparatively small numbers of participants (Larkin et al., 2006; Smith et al., 2022). First conceptualized in the mid-1990s in the UK by Jonathan Smith (Smith, 1996), IPA has quickly risen in popularity becoming one of the best-established approaches to qualitative research. IPA is rooted in phenomenology, in that it emphasizes the detailed examination of rich, first-person accounts of how a participant makes sense of their experiences. In this sense, IPA is a specifically psychological research method (Willig, 2013).

Unlike descriptive phenomenological methods, IPA is also hermeneutical in that it acknowledges that access to the participant's experience is partial, and though efforts are made to get as close to their subjective experience as possible, ultimately the account is constructed by participant and researcher (Larkin et al., 2006). In this way IPA involves a double hermeneutic, with the researcher trying to make sense of the participant trying to make sense of what has happened to them (Smith et al., 2009). Smith (2007) describes the application of the hermeneutic circle in the relationship between the researcher and participant, with the researcher starting off at one side of the circle, reflecting on their own concerns and preconceptions, and then attempting to either bracket, or at least acknowledge these, before moving from this position to encounter a research participant at the other side of the circle and attending closely to their story and experience.

This simplified version of what is a complex iterative, dynamic process, continues throughout the analysis of the material gathered from the participant, moving in a series of concentric circles from single extracts, to the material as a whole, to the context of the participant's whole life, and finally placing it in relation to a wider social, cultural, and theoretical context (Smith & Osborn, 2015). IPA has been widely used to conduct research in both Counselling and Health psychology (Kasket, 2016), often when the topic has a considerable existential significance, such as health and illness, and in explorations of identity changes associated with major life transitions and embodied experience (Smith et al., 2022), all of which are very relevant to HSCT and SCD.

3.2.3 Evaluating different approaches

As we have seen, three previous studies into HSCT for SCD have adopted Content Analysis, but I was keen to bring a new perspective to the exploration of this subject. Content Analysis is a method that is independent of theoretical perspective or framework (Julien, 2008) and tends to restrict itself to the manifest and explicit content of what participants say (Hsieh & Shannon, 2005), which I was keen to go beyond. I discounted the use of Grounded Theory as well, as it seeks to develop codes and categories in order to construct a conceptual,

explanatory level theory in relation to the topic of interest, which is tested and refined through the ongoing identification and recruitment of participants, until saturation, the point at which no new data emerges (Birks & Mills, 2011; Willig, 2021). This was not something I was concerned to do, rather, I was keen to develop a nuanced understanding of the lived experience of the relatively small number of people with SCD who have had HSCT.

Another alternative approach I considered was Thematic Analysis, especially given I had prior experience of using this methodology as part of my MSc dissertation where I investigated the impact of personal therapy on trainee Counselling Psychologists. I discounted this approach as I was interested to move beyond identifying themes (Clarke et al., 2015). I wanted to adopt a more interpretative and analytical approach, placing the participants' experiences and meaning-making into a wider context (Hefferon & Gil-Rodriguez, 2011), which is something IPA excels in doing, and is in keeping with my adoption of a hermeneutic phenomenological epistemology.

Later on, I considered Narrative approaches, which overlap somewhat with IPA in their focus on how people organize, interpret and make sense of experience (Smith et al., 2009; Hiles et al., 2017; Silver & Willig, 2021). Unlike IPA, however, the narrative is the object of analysis, with researchers investigating how people impose order on the narrative and how they place themselves within it (Riessman, 1993). Finally, I discounted discursive methodologies, such as Discourse Analysis or Foucauldian Discourse Analysis (FDA), as these approaches primarily focus on speech and how individuals use language to construct meaning and social reality (Willig, 2013), rather than exploring experience in its own terms, as in IPA (Larkin, 2015).

3.3 Design

3.3.1 Ethical considerations

Ethical approval for this study was gained from the London Metropolitan University School of Psychology Research Ethics Committee (REC). The study adhered to the Code of Human Research Ethics recently published by the British Psychological Society (Oates et al., 2021). In relation to minimizing harm, I did not foresee many risks to participants taking part in this study, though realized it was possible that discussing their transplant might evoke some intense memories and feelings. To minimise the occurrence of distress, participants were explicitly told in advance what the topic of the interview was in a participant information sheet (see Appendix 6) before they decided to take part.

A distress protocol was developed (see Appendix 9) detailing action I would take if a participant did experience distress. In terms of maximising benefit, my hope was that participants would find talking about their stem cell transplant helpful in allowing them to reflect upon this experience, as well as empowering them by giving them the opportunity to share their experiences to help inform other people with SCD considering or commencing a stem cell transplant.

3.3.2 Participants

I aimed to include a final sample of six participants for the study, a sample size which I believed ambitious yet realistic in terms of the number of people with SCD I thought would have had a transplant, and also a size considered adequate by Smith et al. (2009), who suggest an estimate of between four and ten data sets for a professional doctorate, though such a figure is contextual and must be considered on a study-by-study basis. I used the following purposive sampling criteria:

- Aged 18+.
- Living in England and having had the transplant on the NHS at least 6 months prior to participation.
- The indications being that the transplant had been successful.

I chose to exclude people who had very recently completed a transplant, as I reasoned they were likely to still be recovering physically from this procedure, and also those where the transplant was not successful or when people have experienced significant complications, as a one-off interview could evoke the distress and disappointment associated with this and would also result in a less homogeneous sample.

3.3.3 Recruitment

As an incentive to participate, I offered each person a £20 one4all gift voucher, which I anticipated would be sufficient to generate interest, while also being proportionate to the extent of burden involved in participation, and without being coercive. My initial step was to contact the blood cancer charity, Anthony Nolan, who had created a detailed webpage with information about stem cell transplants to cure SCD and were encouraging more people to contact them to share their own stories of having a transplant. They agreed to assist me in recruitment by advertising the study via their quarterly newsletter, patient forum and Facebook page. When this did not result in any people coming forward, they agreed to share

details of the study with the panel of HSCT recipients who had helped them develop their sickle cell information resources.

Another organization I contacted was the Sickle Cell Society and was fortunate to speak directly to their Chief Executive, who offered to make contact with some of the people known to him who had received a transplant and pass on the participant information sheet. Finally, having attended the launch of the aforementioned REDRESS trial in May 2023, I contacted its Senior Trial Manager, who agreed to pass the participant information sheet onto members of their patient advisory group. I also adopted a snowballing strategy, asking participants at the end of the interview if they would be willing to inform other people about the study who might be eligible.

Ultimately, these efforts resulted in the recruitment of six participants in total. To place this in context, I consulted with one of the haematologists who was part of the National Haemoglobinopathy Panel, and they estimated that as of 16th November 2023, 14 adults with SCD had undergone HSCT on the NHS since it was commissioned in 2020 (S. Chakravorty, personal communication, Nov 16, 2023). A significant reason the number of HSCT recipients were fewer than was expected was that the COVID pandemic had placed the NHS on a crisis footing, reducing its capacity to carry out such procedures. Demographic details of the participants are provided in Table 3.

Table 3. Participants' Demographic Information
Pseudonyms have been used to preserve anonymity

Participant		Gender	Age	Months since HSCT
1	Chima	M	39	24
2	Femi	M	36	16
3	Amara	F	31	19
4	Samuel	M	34	10
5	Ola	F	21	20
6	Joshua	M	29	14

3.3.4 Data collection

The type of knowledge I sought to generate was based upon the recipient's unique, subjective experience of having had a stem cell transplant, I decided this would be best elicited via semi-structured interviews. These were conducted remotely using MS Teams, which allowed me to interview participants in different regions of England and removed a significant barrier to participation. It would not have been appropriate to ask participants to travel to a separate site to complete interviews, nor for me to interview them in their homes, given their potential vulnerability and the fact the effects of the immunosuppressant's given to them during the transplant can last 2-3 years.

The interviews were conducted with an interview schedule (see Appendix 11) developed using guidelines by Smith et al. (2022) and further informed by my literature review on HSCT for SCD. Each participant was provided with an information sheet (see Appendix 6) and given the opportunity to consider this information prior to agreeing to take part, and full written consent was taken before starting the interview (see Appendix 7). Interviews took place between 14th September and 16th November 2023, and each lasted between 45 to 60 minutes. They were recorded using a digital voice recorder with password protection. After the interview, participants were given the opportunity to discuss any feelings evoked at length with me, to reflect on their experience of the interview process and to ask questions. Finally, they were provided with a debriefing form with details of organisations they could contact should they wish to explore further any issues raised during their participation in the study (see Appendix 8).

3.3.5 Anonymity and confidentiality

All data were held and processed in accordance with the Data Protection Act (1998). All recordings were kept securely on a password protected digital voice recorder. Interviews were transcribed verbatim, but to maintain anonymity, all identifiable information was removed (names, places, dates, etc.) and each participant pseudonymised. Electronic documents and emails related to data gathering, such as the consent forms, were saved separately from the interview transcript, password protected, and stored on a laptop, which itself was also password protected and only used by the researcher. Participants were informed that short, anonymised quotes from their interview might be used in material such as conference presentations, reports, educational materials or articles in academic journals resulting from the study, but these would not personally identify them.

3.3.6 Stages of analysis

Having transcribed each interview myself, my analysis followed the seven steps for conducting IPA set out in Smith et al. (2009; 2022) and Smith and Nizza (2021).

1. The initial step required me to **read and re-read the first transcript** on multiple occasions, while listening to the audio-recording at the same time, to begin the process of immersing myself in the data. As suggested by Larkin & Thompson (2012), I wrote observations and recollections of the interview in a separate notebook to capture them for future reference and try to ‘reduce the level of noise’ and bracket them off as much as possible.

2. I then began the second step of **exploratory noting** through a line-by-line analysis of the transcript, highlighting things that seemed important to me, and attempting to create a dialogue with it by making **exploratory comments** concerning **descriptive** (WHAT was said), **linguistic** (HOW it was said, including the language used, metaphors, etc.) and **conceptual** (WHY they said what they said, including more abstract, interrogative or interpretive ideas) things of interest within the text (Smith et al., 2009; Smith & Nizza, 2021). These were recorded in the column running to the right of the transcript.

3. The third stage involved the **construction of experiential statements** (formally emergent themes), which were arrived at from analysing my exploratory notes and attempting to produce concise summaries of my understanding of the meaning of what the participant said at specific portions of the transcript. These were recorded in the column running to the left of the transcript.

4. In the fourth stage I **searched for connections across the experiential statements** to see how they fitted together. The approach I used was to cut up the set of experiential statements so each was on separate piece of paper, then placed them on the floor and experimented with moving them around in order to look for groupings and ways in which the statements 'spoke' to one another. The main organizing devices I used for clustering were:

    - Similarity: highly related statements were brought together
    - Subsumption: looking for where one statement could subsume others
    - Polarization: conflicting or contrasting statements were brought together
    - Contextualization: identifying contextual or narrative elements that connected the statements
    - Function analysis: the specific function of statements was considered

5. Step 5 entailed naming **Personal Experiential Themes (PETs)** by giving each cluster of experiential statements a title to describe its characteristics and **consolidating and organizing them in a summary table**.

6. Stages 1 to 5 were then repeated in order to **continue the individual analysis of other cases**, approaching them on their own terms in such a way as to preserve the inductive and idiographic commitment of IPA while, as far as possible, bracketing the 'fore-structures' that were created from analysing previous transcripts, to allow new analytic entities to occur.

7. Finally, in stage seven I looked for patterns of similarity and differences across each participant's table of PETs and then, after some degree of synthesis had emerged, moved to examining this at the experiential statement level, in order to carry out a cross-case analysis of the points of convergence and divergence that existed within the experiences of HSCT for the participants as a whole. This resulted in the construction of a table of **Group Experiential Themes (GETs)**, representing a synthesis of my interpretative analysis of all six cases (see Table 4 and Appendix 13 for a prevalence table with details of how many participants in the study contributed to each GET and subtheme).

3.3.7 Quality assurance measures

In aiming to produce a high-caliber qualitative research study, I followed broad and general quality criteria, such as that articulated by Yardley (2015) and Levitt et al. (2018), and IPA methodology specific criteria, as outlined by Nizza et al. (2021) and Smith et al. (2022). I sought out additional workshops to learn more about how to carry out IPA and ensure my analysis and write up corresponded with its theoretical principles, including one by Professor Jonathan Smith, and two by Dr Elena Gil-Rodriguez.

In order to present a transparent account of my methods and demonstrate the analysis and write up were credible, plausible, and grounded in the data, I have provided a paper trail of the entire process of carrying out the study in the appendices. This includes the interview schedule, a section of annotated transcript from one participant and their table of PETs. Discussions around the construction of experiential statements and theme categories took place during a research workshop as part of the Doctoral programme, in supervision, and with psychologist peers working with people with SCD and also with experience of IPA. Participant validation was considered, but I decided this was not compatible with the methodology of IPA, which is in keeping with the argument by Smith (2004), that interpretations may appear too abstract for participants to legitimately comment upon without a full and detailed account of the process of analysis. Furthermore, I concluded that power imbalances would make it difficult for participants to disagree with my analysis.

Finally, I engaged in reflexivity by critically reflecting on the process of conducting the study and the analysis. Given I had worked with people with SCD for over 9 years, I recognized there was a risk that I would not approach the interviews and transcripts with an open mind. While it is impossible for a researcher to put aside or 'bracket' all of their prior experience, knowledge and assumptions, one of the additional processes I put in place to try to identify

when they might impact on my analysis and findings, was keeping a reflexive research journal to consider how I interacted with participants at all stages of the study and the impact this might have had (Kasket, 2016).

CHAPTER 4: ANALYSIS & RESULTS

"Now I am ready to tell how bodies are changed into different bodies"

From Tales of Ovid, translated by Ted Hughes (1997).

4.1 Overview

A strong temporal sequence of the experience of HSCT emerged from the analysis, and organising the GETs around the three time points of before, during and after the transplant appeared a coherent way of arranging them. A journey metaphor was used by many participants, with the desired destination being a life free of SCD, while the trials and tribulations of the transplant was something that needed to be endured to get there. The comparison made by one participant that living with SCD was like being in hell, brought to my mind Dante Alighieri's (1265-1321) description of hell in the *Inferno.* This episode forms the first part of the trilogy that makes up his *Divine Comedy,* a spiritual autobiography in journey form, with the second episode, *Purgatorio (Purgatory)* detailing an intermediary stage in the journey where the soul has left the Inferno and willingly undergoes an arduous process of transformation that will enable them to reach *Paradiso,* the Earthly Paradise, which is the third and final episode of trilogy.

As my analysis continued, I began to see more and more parallels between this work and the way participants described the psychological ordeals and temporary 'purgatory' they went through as part of their journey towards the longed-for destination of a life free of SCD. I was therefore inspired to raise my level of interpretation and be creative in naming the three GETs after the episodes of the Divine Comedy, with the hope of engaging readers and evocatively telling them a story about the lived experiences captured and reflecting the inductive and human-driven analysis I'd undertaken (see Table 4). I carefully read over relevant threads in the IPA discussion forum on the topic of naming GETs, and discussed them with my supervisor and three other psychologist colleagues who had experience of both IPA and SCD, as a check that they were still being grounded in the data and not straying from the lived experience of the participants.

As documented earlier, there was some heterogeneity in the sample, with a range of between 10 to 24 months since they'd had their transplant, and so where the participant was in their 'journey' appeared to influence their appraisals of it and how they made sense of it. Individual differences and ways of coping were also noticeable and mediated how the isolation and recovery period was experienced. Given the restrictions imposed by the word count, in my analysis and write up I have emphasised those aspects of participants' accounts

which have most relevance to Counselling Psychology and implications for the psychological support that is offered.

Table 4. Group Experiential Themes, Subthemes

Group Experiential Themes	Subtheme	Key Quotes	Subtheme Frequency
Leaving the Inferno	**The growing burden of sickle cell disease**	*"I've always said, if there was, if there was a hell then living with sickle cell would be it, because it's, it's just…physically exhausting and mentally draining"* (Joshua, 21-24)	6/6
	Considering the benefits and risks of the transplant	*"To be given that opportunity that you know, this could be your quality of life, was for me like a no brainer, like I have to, sort of like, go ahead with this because I have a statistical chance that if I did end up being sick again, I could die, and I've had near death experiences, and I'm just like, "it's now or never" kind of thing for me"* (Amara, 95-99)	6/6
Travelling through Purgatorio	**Challenging experiences**	*"I wasn't really prepared mentally for the level of…care that I have to take, the paranoid feelings about picking up infections. The, the stress of getting, you know, being unwell while taking immunosuppression"* (Samuel, 286-288)	6/6
	Ways of coping	*"Filter out all the negativity, and embrace the, the positivity, and fortify your mind from other things that could possibly make you worry"* (Chima, 196-198)	5/6
	Differing attitudes towards psychological therapy	*"I was definitely open to any methods of, of, of getting through the process more easily, erm, and that was one that when I found out it was made available that I was happy to take"* (Femi, 171-174)	6/6
Journeying towards Paradiso	**Getting reacquainting with the body**	*"I feel like 'cause my body has gone through constant crisis and constant pain, it's sort of like programmed itself that OK, after a couple of weeks, or after a couple of days, this is what's going to happen…I feel I'm, I'm at a stage where my body's having to rewrite and relearn certain things"* (Amara, 228-233)	5/6
	Changes in identity	*"It really kind of like cuts my existence into two, like there's, you know, the me with sickle cell, and the me without the sickle cell, and I guess I'm still figuring out the me without the sickle cell, but I will always have like a connection to it. There'll always be…that tie"* (Ola, 331-335)	3/6
	Appraising the impact of the transplant	*"If somebody came to me asking for advice on how my transplant went, despite the things that I've gone through, the unexpected illnesses and everything else, I would still advise them to go for it, because in the long term, I think being free of sickle cell is probably the best thing, is the best gift that you can, you can be given"* (Joshua, 523-529)	6/6

4.2 Group Experiential Theme 1: Leaving the Inferno

This GET uses the metaphor of being in hell, or 'the inferno', to represent the hugely disruptive and negative impact of SCD described in the accounts given by each participant, impacting on both their physical and psychological wellbeing. The way this influenced their motivation and decision to proceed with the transplant, despite the risks, is detailed, with all recipients hoping for a "normal life" with more stability, where they could engage in activities people without SCD could do without becoming unwell or having to put lots of precautions in place. It contains two subthemes.

4.2.1 Subtheme 1: The growing burden of sickle cell disease

As a condition that had featured throughout their lives, all participants described SCD as having severely disrupted their schooling and education, work, relationships with family and peers, limiting and restricting what they could do and achieve, and having a detrimental effect on their mental health. This can perhaps be most dramatically encapsulated in the following quote from Joshua:

> *I've always said, if there was, if there was a hell then living with sickle cell would be it, because it's, it's just…physically exhausting and mentally draining* (Joshua, 21-24)

Hell is understood by most cultures and religions as being 'a state or place of great suffering' (Oxford English Dictionary, 2012). This comparison to living with SCD as like being in hell captured the relentless nature of the physical and psychological effects of SCD, which was very evident in each participants' account, and as mentioned earlier, inspired the poetical naming of each GET. Pain featured prominently in the accounts given by participants, with Joshua saying "I can't really begin to describe how painful an episode is" (23-24), while Samuel was "constantly tired and in some sort of low-level pain" (59-60). Frequent hospitalisations meant that Amara "was having to like sort of like, restart life every time I got admitted" (23-24), which was stressful and resulted in a "constant spiral because then I'm stressed, I'm worried, and that triggers my, you know, sickle cell" (69-70).

Psychologically, participants spoke of experiencing episodes of depression, anxiety, frustration and loneliness. A particularly emotive example of the psychological impacts of SCD comes from Ola's interview:

> *There was just a lot of loneliness in having…the disease. There's just a lot of loneliness in knowing that it was gonna be something I would have forever, and knowing that I wouldn't be able to have…like (begins to cry)…sorry, like…(continues to cry)…sorry...like… knowing I wouldn't be able to have the future…like my peers and everyone around me…um, yeah, it was…there was a very physical aspect to it, but there was also a very, you know, mental aspect to it as well* (Ola, 30-37)

In her description of the loneliness she felt in this and other extracts, Ola marked out how different and isolated from other people SCD made her feel, and that this was an existential state she'd be in forever:

> *I always felt very, uhm, different, or very isolated in almost every area I could think of, not just in like school, but also within my family as well, because I'm the only one who has it within my entire family. So it was, it was kind of something I felt no one*

> *could…really understand in depth what it was like to go through except for, you know, other people who have it* (Ola, 22-28)

She proposes the experience of living with SCD is something imaginable only to people who have it themselves. For Ola, having it forever and knowing that she wouldn't be able to have the future her "peers and everyone" around her would have, separated her from other people, and clearly the distress and psychological impact of this was still very present for her even 20 months on from having had the transplant.

Another factor spoken about by participants was the way SCD had been getting worse over the years, with more frequent or severe crises and the accumulation of complications such as organ damage and avascular necrosis. One of the participants had suffered a major stroke and another had a hip replacement in his early 20s. Ola described having been "getting sicker and sicker over the years, and nothing was really helping it" (80-81), while for Samuel "sickle cell became more of a problem as I got older" (33) and the sickle cell crises he had "were more severe, would kind of have some kind of complications with them" (37-38). Chima summed up the prognosis for his future by saying "I can't see how this gets any better" (131), imagining the burden of SCD and complications only increasing in the years ahead of him.

4.2.2 Subtheme 2: Considering the benefits and risks of the transplant

Weighing up the risks of having the transplant and ultimately deciding to proceed with it, was a process each participant spoke about in detail. As highlighted in the previous subtheme, the worsening of SCD over time was a major reason for having the transplant cited by all participants. The experience of never having known a life without SCD and comparing it to an idealised normal life, is something several participants also spoke about, as illustrated in this extract from Amara:

> *It was just to have a normal life. To be able to wake up and not worry about, you know, me feeling pain or having to think of what sort of, like clothing I'm going to wear, because any little thing can trigger, you know, my crisis and like, you know, so that was one of the first things I was just thinking about, "Oh my God, what, what will my life be like without sickle cell?"* (Amara, 86-92)

As with other participants, imagining a life liberated from the 'abnormal' burden of having to worry continually about becoming unwell and possibly dying was for Amara highly influential in her decision to proceed with the transplant:

> *To be given that opportunity that you know, this could be your quality of life, was for me like a no brainer, like I have to, sort of like, go ahead with this because I have a statistical chance that if I did end up being sick again, I could die, and I've had near death experiences, and I'm just like, "it's now or never" kind of thing for me* (Amara, 95-99)

It being a "no brainer" suggests for her it did not require lots of deliberation, though she rhetorically said "Did I have worries? Yes, I did, but it wasn't a hard decision for me" (103). Dying as a result of the transplant wasn't one of the worries she reported:

> *There's a percentage that you could die as well, but I feel like that really wasn't my worry, because I was like, I could die anyway at any time, but I feel like the extra complications that can come in, in case, you know, if it didn't work out, that was my main worries* (Amara, 110-115)

The existential experience of facing their own mortality is something most people with SCD have had to deal with from an early age, and Amara and other participants seem to have not been daunted by the relatively low risk of dying associated with having the transplant, knowing that as their SCD had become more severe over time, their risk of dying was increasing anyway.

The unfamiliar prospect of developing complications due to the transplant, or of it failing, was a source of worry for Amara and other recipients, though the extent to which they described consciously considering the risks and other negative outcomes of the transplant varied. For Ola, her longing to be free of SCD meant that deciding to have the transplant "didn't need any consideration, it was something I immediately knew that I wanted to do" (104-105).

> *The risks were all stated out to me, but like I said, I had absolutely no concern for them. All I could think of was finally not having sickle cell and that was the only thing that was ever guiding my decisions, to be honest* (Ola, 117-119)

Later in her interview, Ola thought she had minimised the significance of the transplant when appraising what might happen, saying she has:

> *A tendency to just...not try and like make too big of a deal of things that maybe are a big deal. It's just, I just thought of it as "Oh, I just have to get through this for a few weeks or months and then I'd get to where I want to be"* (Ola, 145-148)

As with Ola and Amara, for Joshua:

> *When they offered it to me I, I didn't even have to think about it too much before I said yes. And this was because I sort of always knew that the red cell exchange was always a temporary, temporary fix, it wasn't a permanent thing* (Joshua, 102-105)

This being a permanent cure rather than the "temporary fix" offered by other disease modifying treatments, was also persuasive for Samuel, whose decision to have the transplant was confirmed by a consultant haematologist he'd known since he was 18 years old telling him "The transplant is effectively a cure, everything else that we could offer you is some sort of palliative care" (212-214). Samuel described having wanted:

> *Honesty about whether or not I should do it, and, and in those terms, it's kind of like, "Well, yeah, why wouldn't I?" But like I said, I was, I was...I'm strong enough in my kind of convictions that, you know, I was, I was going to do it anyway* (Samuel, 215-220)

His emphasis that having the transplant was a personal choice was apparent in a number of places, linked to his familiarity with living with SCD and ability to manage it:

> *I certainly, erm, could have lived the rest of my life without having a transplant…I knew how to manage the condition, so it was a risk because I didn't absolutely have to do it, it wasn't life or death, I've met people for whom, you know, they've had numerous strokes and it can be life or death to have the transplant…and I've met people who are in hospital every week of their lives…I'm not either of those things, so I had to think about whether or not it was the right thing to do, to put myself under quite so much…it was definitely like a kind of knife edge decision and there's, you know, a parallel universe where I don't have the transplant.* (Samuel, 156-170)

Samuel later mitigates this somewhat by saying "I wouldn't say knife edge, maybe that's overdoing it a little bit, but I would have been justified in not having it, and I would have been justified in having it, and I decided to have it" (176-178). Samuel's description reveals a degree of deliberation not apparent in the participants considered so far, with the pros and cons of the transplant seemingly fairly balanced, and with his decision being of his own volition to embark upon the unknown and uncertain experience of having the transplant, while acknowledging he could have chosen not to. He did describe intentionally not deliberating excessively, however, reflecting that "You can get into a kind of rabbit hole, where if you analyse, over analyse it, then you talk yourself out of it…I consciously didn't do that" (318-320).

Femi expressed the most deliberation, describing it as a very difficult decision to make:

> *The actual process of determining to go ahead with it, certainly my experience of it was the amount of, um, things to factor in and decide about that are, that were potentially irreversible, are things that, that weighed heavy when deciding to go ahead with it, so things like fertility, and the risk of, of kind of rejection* (Femi, 338-344)

The phrase "weighed heavy" is suggestive of some lingering doubts and concerns, or perhaps reflects the significance of potential side effects and complications when 'weighing' up the pros and cons of the transplant. As with other participants, he was satisfied with the information provided to him, though acknowledged he probably hadn't "immersed every single detail" (125), and thought due to the excitement of having the transplant and people's naturally optimistic outlooks, they would "only want to look at the upside of the outcome, so I think it's a human thing to do" (128-130).

4.3 Group Experiential Theme 2. Travelling through Purgatorio

In Dante's *The Divine Comedy, Purgatorio* is the place where the soul is gradually transformed, cleansed and purged, in readiness to reach Paradisio. Today, the term 'purgatory' is often used to refer to 'a place or state of temporary suffering or misery' (Merriam-Webster, n.d.), while to 'purge' is defined as to get 'rid of an unwanted feeling or condition' (Oxford English Dictionary, 2001). This seemed to capture the way participants viewed the HSCT process as an arduous experience they willingly underwent in order to be free of SCD. The GET consists of three subthemes, covering the challenging experiences they had during HSCT, how they coped, and their attitudes towards psychological therapy as a way of supporting them through the process.

4.3.1 Subtheme 1: Challenging experiences

When asked about his most prominent memories of the transplant, Samuel responded "I would very much class the time before and during the transplant as one area and then the time afterwards is completely separate, I would argue" (231-233). This time separation resonated with the accounts of other participants. Samuel described the transplant itself as:

> *Quite low key, underwhelming kind of transplant itself, the transplant day. I mean, it was a little bit scary, but it wasn't, you know, like quite a big Hickman line gets put in, in that kind of thing, but nothing great, nothing that is completely, you know, nothing I couldn't handle, I could put it that way* (Samuel, 246-250)

Their experiences living with SCD, being in hospital, and having blood transfusions, meant that for most participants this phase of the transplant felt familiar and manageable, especially since they weren't acutely unwell at the time of going into hospital. Femi also remarked on how "the actual transplant itself was remarkably…unremarkable, given it's, it's just almost like a blood transfusion" (70-71), something echoed by Ola:

> *I think I was actually quite surprised at how like easy, I suppose it was, 'cause it was kind of just like a transfusion, but, uhm, well, the process of having the transplant…'cause before I'd, whenever I thought of like bone marrow transplant, I thought it was like some big operation or something* (Ola, 138-143)

Some participants spoke of a mixture of excitement and anxiety in the build up to the transplant, and even though a number of them described being sick as a result of the conditioning regime, this was also reported as mostly being expected and manageable. For example, for Samuel the chemotherapy "certainly wasn't nice, but I'd kind of prepared myself for, for the worst with that" (252-253).

In contrast, the time following the transplant was described as much more difficult by all the participants. For Ola:

> *I just was probably at my worst after the transplant, 'cause. I just felt so out of myself, but I just, I don't know. I just kept thinking, you know, this is just what I had to do to get to the finish line* (Ola, 151-154)

Ola appeared able to reframe the experience of being unwell and isolated as tolerable by having so readily in mind the impact of sickle cell and awful experience of having a painful episode, and reminding herself any challenges she was experiencing were necessary to be free of SCD:

> *Honestly, I would say even up till today I'm still recovering from that…I think I started to feel, to actually start getting better, maybe like six months post-transplant, but even as like bad and like down I was those months, I'd, I, I still felt like it wasn't anything as compared to being in like an actual pain episode* (Ola, 160-165)

The length of time recovery took was something that most participants described not having fully appreciated, and for Femi challenged his expectations:

> *You kinda go in thinking it's like a switch, but it's less of a…it's less of a definitive switch that way, it's more of a gradual process* (Femi, 97-99)

Unlike the straightforward procedure of receiving the donor stem cells, the overall transplant process was longer and more gradual than participants had anticipated, with regular follow up appointments and blood tests required. The length of time they needed to take immunosuppressant medication also exceeded expectations. Samuel touched on this, when describing the difficult experience of having picked up two serious infections while immunosuppressed:

> *I wasn't really prepared mentally for the level of…care that I have to take, the paranoid feelings about picking up infections. The, the stress of getting, you know, being unwell while taking immunosuppression medication* (Samuel, 286-288)

He again contrasted this with the experience of receiving the transplant, for which he felt mentally prepared:

> *I was fully kind of ready for, erm, the…what would happen in hospital, I just wasn't necessarily ready for what would happen kind of months down the line afterwards* (Samuel, 299-301)

Recall earlier, his statement about knowing how to handle sickle cell, and compare this to the psychological impact upon him of the unfamiliar experiences and uncertainty of being immunosuppressed. This is a markedly different state of being-in-the-world to the familiar parallel universe he earlier described where he didn't have the transplant.

Getting sick following the transplant and the recovery taking longer than expected was also very prominent in Joshua's account:

> *The initial plan was to be in hospital for..., uh, about a month, really, the whole thing...was supposed to last a month, uhm, that was the plan, but uh, you know, I got really unwell afterwards. Ended up staying for about close to three months* (Joshua, 207-210)

During this period of ill health, he said:

> *I did start to doubt, you know, my decision to, to do it, because I was also away from work for three months. And it, it's unplanned. I had planned a month away with my employers. But not three months* (Joshua, 257-259)

Joshua was the only participant who spoke of seriously questioning his decision to have the transplant, which reflected just how unwell he was at the time, though this passed once he began to recover. Samuel, who as we have seen, was also unwell after picking up two

infections, spoke of having days where he thought “why did I do this?” (311), but said he’d never seriously regretted it.

The period of isolation required while being immunosuppressed was described as hard by several participants, with some mentioning the COVID pandemic as an added stressor, though most thought it manageable. Joshua said:

> *It's hard, but it's not that hard, it's doable, especially for me, because you know I'm, I'm an introvert, so I, I'm not really too fussy about being out all the time* (Joshua, 348-350)

This categorisation of himself as an introvert highlighted what appears to be prominent individual differences in how this period of inactivity and isolation was experienced. Samuel also described being able to keep himself occupied and okay being alone, though for Ola she associated it with the repeated experiences of loneliness and isolation caused by SCD she’d had, which left her feeling low in mood. Amara portrayed herself in the most extraverted terms out of all the participants, and she found the isolation and recovery period the most challenging, as we shall examine in more detail in the next subtheme.

4.3.2 Subtheme 2: Ways of coping

Continuing on from the last subtheme, participants described a variety of coping strategies during the lead up to the transplant and in the weeks and months following it. Some of the participants’ ways of coping seemed to have been formed in response to the negative effect of sickle cell upon their lives, and at times were more or less helpful in coping with the transplant. In the previous subtheme, I explained that Amara had found the period of recovery and isolation most challenging, which appeared related to her description of herself as being a highly sociable and active person. She commented on the realisation she’d coped with SCD by keeping busy, and acknowledged that when she is still, she can “kind of get in my head” (177). Whilst in hospital she applied a similar approach to responding to the transplant:

> *I tried to keep myself busy by recording on YouTube my day-to-day routine, so that, you know, if anyone else is to go through what I'm going through, they kind of know what's to come, kind of thing, just kind of giving as much information out there as possible. So, I used that to kind of, erm, (laughs) distract myself during those moments* (Amara, 200-205)

Whilst serving as a way to distract herself, Amara was also able to make such activity meaningful and altruistic by documenting her experiences as one of the first people with SCD to undergo HSCT in England and turning them into something she hoped could help other people with SCD understand what to expect if they chose to proceed with a transplant. After the transplant, while being advised to socially isolate and allow time to recuperate, this coping style appeared less adaptive:

> *Still at an early stage with the transplant, obviously they advised you not to work because it is a lot, uhm, it's a lot of changes, your body's going through a lot. But I went into work a lot earlier…just because of my mental state, I felt like I couldn't not work if, if that makes sense. Like I needed something to sort of, like, distract me from everything that was going on, from the changes, and like, I didn't know how to…(sighs), it's, it's so bad, but I didn't know how to stay still and just allow the process of, you know, my body changing and everything that's happening, take place, and just take time to like really recuperate properly. And I feel like that stemmed from having lived a life of sickle cell. The unpredictableness of it has made me…not take breaks and, and, you know, just constantly rushing forward and…so whilst I was still in the process of being healed…still heavily medicated, I spoke to my consultant at that time, I was like, "I can't take it, I need to work"* (Amara, 395-411)

Here Amara reflects on the legacy of living with the unpredictability of sickle cell, and the drive to accomplish things when able to do so. Her need to escape from the difficult emotions experienced during the isolation and recovery period appear to elicit feelings of guilt and/or embarrassment, supported by her statement that "it's so bad" when talking about her inability to be still and recuperate properly. In relation to work, earlier in her interview Amara had spoken of herself as being "someone that's such a hard worker" (56), so this period of inactivity may well have also presented a threat to this identity. Fortunately, Amara did not suffer any negative consequences as a result of returning to work early, such as picking up any serious infections.

The strategy of keeping busy to avoiding thinking too much was adopted by Samuel in the lead up to the transplant:

> *I was working very hard up until the transplant, uhm, maybe, and in retrospect, I think I was probably over com…, yeah, the more I work, the less I had to think about the transplant* (Samuel, 462-464)

He recognised that by keeping busy he prevented himself encountering some of the worries and doubts he may have experienced. Later, he seems to be concluding this avoidant way of

coping played a part in him having not been “mentally prepared” for the experiences he had following the transplant:

> *I underestimated how, how big a decision it is to have…a…bone marrow transplant. Uhm, I probably, avoided acknowledging that it is a significant life changing event that I was volunteering to have happen, and that I should kind of treat in that way as opposed to, you know, just another crisis, in that I go in and then come out and get on with the rest of my life. It's not that, it's quite, it is a big undertaking* (Samuel, 380-386)

This statement about his having volunteered to have such a significant life changing event, calls back to some of his earlier comments where he had emphasised he’d have been justified in deciding whether to have the transplant or not. He also appeared to assign some responsibility to himself for having picked up two infections while immunosuppressed, reproaching himself by saying “maybe I didn't ask enough questions about that side of things” (290-291) and maybe he’d “rushed things a little bit” (298).

Efforts to avoid thinking about negative outcomes were most powerfully articulated by Chima:

> *Filter out all the negativity, and embrace the, the positivity, and fortify your mind from other things that could possibly make you worry* (Chima, 196-197)

This seemed especially important to him when following the transplant there was a degree of anxiety within the healthcare team that the transplant could fail as he developed GVHD. The newness of the procedure and lack of experience of staff members in carrying out HSCT for people with SCD, was something mentioned as worrying to Chima and two other participants. In response to this uncertainty and anxiety, Chima said:

> *I just had to keep staying in a positive area, keep praying, keep, you know, speaking to my dad, who I was speaking to almost every other day, speaking to my wife, every single, every other hour basically, um, yeah, and stay focused on the ultimate goal basically, which was once I got out, I wouldn't have to worry about sickle cell pain and crisis anymore* (Chima, 207-211)

Here, Chima talks about retaining a focus on the ultimate aim to be free of sickle cell and keeping himself occupied in the face of what were alarming conversations occurring around him. Joshua, Femi, Samuel and Ola were also able to make sense of their difficult experiences of being unwell and isolated by reminding themselves this was a temporary part of the process of permanently getting rid of SCD. Chima’s emphasis was on what he could control,

which for him was his own mind, rather than focusing on what was happening with his body and the transplant, which were not in his control:

> *It was more a mental battle as well and I didn't like…I felt even if I lost the physical, I don't wanna lose the mental battle, I mean…um, yeah, and that was important. That was actually really, really important to me going in* (Chima, 256-258)

This metaphor of it being a battle is suggestive of him viewing himself as a warrior, fighting and defending himself against 'negative' thoughts and feelings, which was important in maintaining his sense of self-efficacy. This seemed to be a battle he needed to fight himself, with the strong support of his family, which as we shall see in the next subtheme, had implications for his attitude towards of psychological therapy.

4.3.3 Subtheme 3: Differing attitudes towards psychological therapy

Dante was guided through purgatory by Virgil, the great Latin poet. All the participants were offered psychological therapy to help them through HSCT, though they held differing attitudes towards this. Chima's approach to coping with the transplant carried over strongly to his attitude towards being offered psychological therapy and declining it:

> *What I did not want was someone else to come and sort of…break up my foundations, and give me reasons to doubt myself. Because if I'd spent so long building, erm, building my foundations and building myself basically, and something that could possibly… because I was a bit down, would be able to penetrate my, um……shield, so to speak then… I didn't want...I didn't want to give myself that opportunity, basically, if that makes sense* (Chima, 239-247)

As with earlier extracts, here he again seems to be drawing on the metaphor of a battle, with him holding a shield and the psychological therapist being a potential threat who could expose any vulnerability "because I was a bit down". In contrast, on his side in this battle were his family, and he was adamant "I can't over emphasise having a strong support system" (505), while in a later part of the interview Chima speaks of the importance of his Christian faith, which appears to form an important part of his foundations.

Joshua also expressed a view that psychological therapy was not helpful for him, having met with a therapist whilst in hospital when he was feeling very unwell:

> *I felt like…(sighs) at the time, I felt like speaking to somebody wasn't really helpful, because……I didn't really have too much to talk about, to be honest, and I also didn't*

> *feel like they had, or they could help me in any way. Cause they just stood and listened to me talk and there was no sort of real input back from them, uh, so I didn't feel like he was helpful at the time, even now looking back, I still don't feel like it was helpful* (Joshua, 278-284)

While his being physically very unwell at the time may have affected his capacity to enter into a dialogue with the therapist, Joshua also spoke about the very strong support he received from his mother who visited him "pretty much every day for the, the whole three months" (291-292) he was in hospital and helped maintain his psychological wellbeing, in a similar way Chima's family had done for him. Of note, both Chima and Joshua were the only two participants who grew up in African countries, and so there may also have been a cultural element to how they appraised the prospect of entering psychological therapy.

More neutrally, Amara met with a psychological therapist once, but explained "at the time I didn't feel like I needed it" (197) because of the support she had from friends and family, though in retrospect thought it could have been beneficial, saying:

> *There's certain things that you can tell your family members, but then there's also things that you sort of like keep to yourself, and you can only expose to like, a stranger, which is so weird, because I feel like everyone does that* (Amara, 217-220)

Ola was referred for psychological support, which she found "helpful when I really was at my lowest and felt I needed to talk to somebody" (203-204), though only had a few sessions. She reflected this was "partly on me, erm, for not following through with them…" (208-209) suggesting the onus was on her to reach out for this continued support. Her feedback at the end of the interview, however, indicates that having the opportunity to emotionally process her experiences was welcome:

> *Honestly, I, I feel like I've got a lot out today. This is probably like the first time I've ever like spoken about it in depth, so yeah, it's quite good (laughing). It feels quite cathartic, it feels good to have said all of that* (Ola, 451-455)

Samuel and Femi were much more favourable towards receiving psychological support to help them through the transplant, with Femi saying:

> *I was definitely open to any methods of, of getting through the process more easily, erm, and that was one that when I found out it was made available that I was happy to take* (Femi, 171-174)

This was informed by:

> *Reading through experiences, learning through other people's experiences, I was conscious of the fact that it could certainly be gruelling mentally and emotionally so, erm, it was…I didn't ask for it, but I was glad to take it* (Femi, 176-179)

So, while he didn't actively seek out therapy, he was receptive to this when it was offered to him as an integrated part of treatment, finding it particularly helpful during the recovery and isolation period:

> *There were a bunch of regular, sort of exercises to help with, with motivation and help with, with...I guess the lack of drive and the boredom that comes with that long period of just doing not a lot. So that definitely helps with kind of staying plugged in, staying upbeat. Uhm, there is a period where you're not really physically able to do much and so it does lead to, to feelings of uselessness, and keeping perspective through that was useful* (Femi, 158-164).

Part of this keeping perspective entailed taking a longer-term view and reminding himself of the hoped-for outcomes of the transplant and the transitory nature of his challenging experiences, a strategy engaged in by Chima, Ola and Joshua without the input of therapy.

Finally, Samuel spoke of therapy as being "massively helpful" (257) in making sense of his experiences, related to his view he'd underestimated the significance of the transplant:

> *Making that kind of big decision, I think was probably affecting other parts of my life as well, so, uhm, I probably didn't realise it at the time and so…having that, having someone to talk to, to just kind of piece it together, I think was, was, very helpful* (Samuel, 358-361)

For him, he'd started the therapy himself independently from that offered by the transplant centre and prior to having HSCT, though he carried on with it, realising it was beneficial in processing his experiences, especially the challenges he faced with being immunosuppressed and picking up infections. He was continuing with this therapy at the time he was interviewed, and spoke of the way this was helping him adjust to the unfamiliar life without SCD, which brings us to the final GET.

4.4 Group Experiential Theme 3: Journeying towards Paradiso

Paradiso is the third and final episode of Dante's Divine Comedy, detailing the poet's ascent to reach paradise. In English, paradise is a word used in common parlance to refer to 'an ideal or idyllic place or state' (Oxford English Dictionary, 2001). This seemed an apt way to

capture the progress towards a more 'normal' life participants hoped for after the transplant. The journey metaphor was again used by a number of participants. This group theme consists of three sub-themes, capturing the ongoing adjustment to life without SCD and the impact of the transplant.

4.4.1 Subtheme 1: Getting reacquainting with the body

Following the transplant, five of the six participants spoke in detail of consciously monitoring bodily sensations and experimenting with physical activities that they would have previously avoided for fear of causing a sickle cell crisis. They varied in how cautious they were in this, reflecting individual differences, with some participants trying things out more slowly and gradually, whereas others, such as Chima, took an experimental and bold approach:

> *One of the first things I did, as soon as I started stepping out was go to the gym, erm, for a good…seven years I wasn't able to go to the gym because anything that resembled like a gym just looked like it was pain, basically…but I used to go to the gym like very religiously, umm, for at least for the first six months, basically trying simple things like drinking cold water, I never used to drink a lot of cold water…erm, but now I can, yeah, I do drink a lot of cold water now, umm…Yeah...it's just, it's like seeing "OK, so what can this new body do?"* (Chima, 294-304)

Chima seemed to have actively tested the limits of what his body was capable of, deliberately doing things that would have previously caused him to become unwell. His classification of this "new body" seems to suggest he sees it as a new object he has acquired which he needs to get acquainted with in order to learn what it can do, in comparison to the familiar old body he previously had with SCD. While engaging in more strenuous activity, however, he remarked:

> *Occasionally it's "OK, maybe I've over exerted myself" or something like that, I would worry if actually it's a crisis coming back, erm, but it goes as quickly as it comes, basically, it's not really part of me at all (Chima, 464-466)*

The body still appears to be a potential source of threat and the mental associations are strong between physical sensations that arise when doing particular activities and the anticipated experience of pain and having a sickle cell crisis, though he categorically states he no longer sees it as being part of his identity.

This experience of adjusting expectations of the consequences of engaging in previously avoided activities emerged in each of the participants' accounts. For example, Samuel spoke

of learning to ride a bike and the novelty of engaging in such activities he couldn't do before. He summed this up by saying "I know how to live my life with sickle cell but I'm, I'm learning, I don't quite know how to live it without it, yeah, so it's a bit of a figuring out process" (437-439). He also described experiencing physical sensations that were appraised as potential threats:

> *I'm probably still waiting for…some kind of sickle event, I guess…so when I had sickle cell, you know when I had, so I'd make a run and I'd get like a sharp pain, and then obviously if I, if I kept on running or whatever, it would then escalate into something bigger. I still get these, kind of like, very brief, but sharp kind of pangs, and then you're like, "Oh, what's about to happen?" And then nothing happens and...it's a bit, I guess they're not phan…, I don't know if they're phantom pains, maybe they are, I don't know* (Samuel, 409-4196)

The building of confidence and trust that their bodies would no longer throw them into an intensely painful crisis was described as a gradual process of adjustment by the participants. Ola said when doing things, such as going out for a walk in the cold in winter, that "it sometimes feels like…I'm just waiting, for like the next crisis to come, and it just hasn't come yet, and, and you don't know if that feeling's always gonna be there" (301-303). Ola cannot predict if these feelings will ever resolve and appears to still be in a process of updating the assumptions and expectations she has about her body in light of her new experiences. Amara also described this process succinctly:

> *I feel like 'cause my body has gone through constant crisis and constant pain, it's sort of like programmed itself that OK, after a couple of weeks, or after a couple of days, this is what's going to happen…I feel I'm, I'm at a stage where my body's having to rewrite and relearn certain things* (Amara, 228-233)

In this quotation, Amara seems to be eloquently explaining the gradual alteration and reprogramming required to dampen down the sensitisation and learnt habits that had occurred in her body as a result of repeated episodes of sickle cell pain over many years. This process of adjustment called upon her to learn how to let go of the well-established compensatory behaviours she described earlier in relation to the unpredictability of her health:

> *I am having to learn to not overdo things, 'cause I've been so programmed, if when I'm feeling better, overcompensating to make sure that when I'm not well, you know, things already been put in place and I feel like I'm still having to sort of like break down that wall and it's still a struggle for me* (Amara, 319-323)

This “breaking down that wall” points to the obstacle her previously held assumptions and compensatory behaviours presented, which she suggests will take strength and determination to dismantle in order to complete the transition to accepting she has a body that is no longer afflicted by SCD. Her earlier statement that she “could die at any time” and feeling she had a limited amount of time available whilst having SCD orientated her towards how to live her life, and accommodating her new experiences presents her version of the task of learning to live without sickle cell described by Samuel earlier.

4.4.2 Subtheme 2: Changes in identity

Ola, Amara and Samuel all spoke in some detail of how their sense of themselves had changed since the transplant, while the remaining three participants spoke of this more briefly, for instance saying they no longer saw sickle cell as part of them, and describing alterations in their social roles, with friends, family, and other people. For Ola, her altered sense of herself in the world included a “whole different outlook than before” (315) where she became less self-conscious and more “appreciative of many things” (317), alongside unwelcome changes such as weight gain.

> *Although ironically, this is like what, what I've always wanted, it just feels like I'm not the person who even wanted it in the first place, I just feel like I'm someone else now. Maybe both physically and emotionally, because I'm just so far from…the person I used to be* (Ola, 277-282)

Her sense of identity had been radically changed in the 19 months since she embarked upon her transplant journey, as illustrated in this extract:

> *I feel like I’ll always have a connection to sickle cell, you know, that's, that will always be there, but sometimes it makes me emotional to think I'm gonna live like an entire life now without it. And so much of my life previously was so defined by it. It really kind of like cuts my (laughs) existence into two, like there’s, you know, the me with sickle cell, and the me without the sickle cell, and I guess I'm still figuring out the me without the sickle cell, but I will always have like a connection to it. There'll always be…that tie* (Ola, 328-335)

Her comment that it “cuts my existence into two” is a particularly striking statement, getting straight to the heart of the transformative power of the transplant, but also pointing to how this figuring out “me without sickle cell” is an ongoing process that will take time to

complete, perhaps including how to integrate her previous existence of being a person with sickle cell into her new identity.

Amara also spoke of changes in her identity and feeling like a "completely different person" (266) at times, though interestingly, unlike Ola, she didn't view herself as someone without SCD:

> *I don't see myself as someone without sickle cell, because I still have sickle cell, I just don't have the pain that comes with it or the, you know, the side effects that comes with someone that has sickle cell. I would say I considered myself more of someone that's, that has the trait than, than actually has the full, the full-blown sickle cell* (Amara, 287-291)

This appears to be a perspective which for her successfully integrates the fact that while after a successful transplant she is no longer afflicted by sickle cell pain caused by vasu-occlusion, or will suffer further organ damage, she does continue to have a mix of blood cells from her own and from her donor's stem cells and carries the HbS gene. In this extract her continued connection to SCD is made explicit and clear. In contrast to Amara's more definite conclusion, Samuel was still trying to adjust to his current status and identity:

> *One of the bits of figuring out is, you know telling, I find it very strange to tell people that I don't have sickle cell. Or if I'm filling out a form or whatever, 'cause it's, it's, I guess it's technically true, is, I mean, it is technically true, but also, it's very…is it true? I don't know, it, it just, it doesn't feel...it doesn't make sense yet* (Samuel, 480-484)

Samuel here speaks of intersubjective experiences and the confusion and uncertainty he feels communicating with others, even questioning himself "is it true?" when describing the scenario of explaining his health status to other people or completing a form and stating he no longer has sickle cell.

> *I haven't yet found the form of words that explain, I'm sure, I'm sure it's, you know, other people have had it, I'm sure there's a very straightforward way of explaining it, but…"I'm Samuel, I had sickle cell", and then, you know, it'll become "Whoa, what do you mean you had…?", you know, I don't know really, how yet to kind of approach it, to be honest with you, I think that probably is one of the bigger impacts* (Samuel, 489-495)

Grappling with this, Samuel acknowledged a degree of avoidance in talking to people while he works this out for himself, and in this extract, he seems to be imagining different scenarios and possible reactions. Samuel did also speak of the transplant strengthening his pre-

transplant perspective that life is short and it being important to make the most of his time alive, but this didn't amount to the "whole different outlook on life" described earlier by Ola.

4.4.3 Subtheme 3: Varying appraisals of the impact of the transplant

There was some variation in this theme, which can be partly understood as associated with the extent to which the participant had become sick or experienced complications as a result of the procedure, but also seemed related to the length of time that had passed since the transplant took place, and therefore the degree to which they'd recovered. The most positive accounts came from Amara and Ola, who'd had their transplants 19 and 20 months ago respectively. Ola spoke of the immense gratitude and disbelief she felt:

> *It feels surreal sometimes to think, you know, I've actually been cured. Like to think I had the disease that I thought was gonna rule my life forever, I no longer do, it's, it's very…it's impossible to explain like how mind blowing it is sometimes* (Ola, 350-353)

Recall her earlier statement where she'd become tearful while describing sickle cell as something she would have forever and knowing she wouldn't be able to have the future like her peers and everyone around her. The immense gratitude that "the disease" would no longer "last forever" and "rule" her life was palpable in her responses, with it seeming SCD was cast as a sort of malevolent entity that had been finally vanquished with her being "cured". Ola appears to still be mentally coming to terms with the enormity of the difference the transplant has made to her life, captured in such phrases as "surreal" and "mind blowing". Since the transplant, she spoke of relishing the novelty of:

> *Going camping, or just like going swimming in, in the ocean, it's just like...little things that I knew had I have done it, it could have possibly like triggered me to have a crisis. It's, it's, you know, you'd be surprised, it's literally just things that would seem normal to anyone* (Ola, 370-374)

Note again the use of "normal" as a descriptor. Speaking for both herself and her family, she described them as all being "grateful and in disbelief" (426), conceding "it's an adjustment" (418) as they all update their expectations of what life is now like for them all. Amara also spoke enthusiastically about the success of the transplant, seeing a "life transformation" (271) and the relief and happiness she felt, and as with Ola, appeared to be close to her longed-for goal of a 'normal life' liberated from the restrictions placed upon her by SCD.

Femi, who'd had his transplant 16 months ago, was more cautious in his assessment, setting a two-year window of observation before making any firm conclusions about its impact. Some individual differences appear to be operating here, given Femi had described the most caution and deliberation in deciding to have the transplant. He acknowledged that:

> *That's a personal sort of choice, right? It's an arbitrary personal choice, there is no scientific basis for that, it's just, it's a wide enough window to say, oh, erm, for two years, um…these are differences that… these are the differences or the impacts that, that are identifiable* (Femi, 225-229)

After these two years had elapsed, he thought he'd be able to make more definite plans for the future, but explained he was still psychologically processing the implications of the transplant:

> *I think it's taking a little bit of time to, to get that mindset shift, but that's also an ongoing process that's happening, it'll just, to allow the reality to set in* (Femi, 315-317)

Samuel's transplant had been the most recent, at 10 months earlier, and as we have seen, he'd been quite unwell after picking up two infections and was still on immunosuppressant medication at the time of the interview. He explained:

> *It's just a bit of a halfway house at the moment, it's kind of, it has worked, I don't have sickle cell anymore, but I just need to, erm, navigate this weird space so that I can then mentally be like, "OK, what's next?"* (Samuel, 608-611)

This "weird space" and "halfway house" mark a particular transitionary period in his 'journey' where he describes himself as being fitter than he was, but not yet fit enough to do all the things he wants to do. He went onto say:

> *I've never really seriously regretted it, but I've certainly had days where I've thought "why did I do this?" you know? So, it's a bit of a, kind of, journey, and as I say, I'll come out of it in a years' time and be very grateful, because I won't be in hospital, but you know, it's a, it's a…bigger thing than I had acknowledged beforehand* (Samuel, 310-314)

Whilst being in this transitional stage Femi, Samuel and Joshua all used time projection to look forward to when they will no longer be immunosuppressed and can be more certain the transplant has been successful. For Joshua, this entailed looking forward to a time when he could live life "as a normal person, normal human being" (472), which is the longed-for goal.

Summing up his current appraisal of the transplant, he concluded “I guess it's a win-lose situation, probably the best way I can put it” (434-435) because while he no longer had to worry about sickle cell, he did have to worry about other health complications related to having had the transplant, which could be permanent. However, he expressed no regret:

> *If somebody came to me asking for advice on how my transplant went, despite the things that I've gone through, the unexpected illnesses and everything else, I would still advise to go for it, because in the long term, I think being free of sickle cell is probably the best thing, is the best gift that you can, you can be given* (Joshua, 523-527)

Despite the current win-lose situation, he appears to still hold onto the hope over time this will shift towards more of a ‘winning’ situation as he is able to fully make the most of the “gift” he has been given of being free of sickle cell.

Chima’s transplant had occurred the longest ago out of all the participants, being 24 months prior to the interview, yet he continued to struggle with health problems and organ damage caused by sickle cell, saying “it's not had the impact that it would have” (359-360) and “even if a lot has changed…with the stem cell transplant, a lot hasn't” (413). He went onto rhetorically ask “Why did it take so long?” (370), pointing out that if he’d been offered the transplant earlier, before developing sickle related complications:

> *Life would have been a lot easier and that would have been a lot cheaper for the NHS. So, I still don't know why it took so long* (Chima, 371-372)

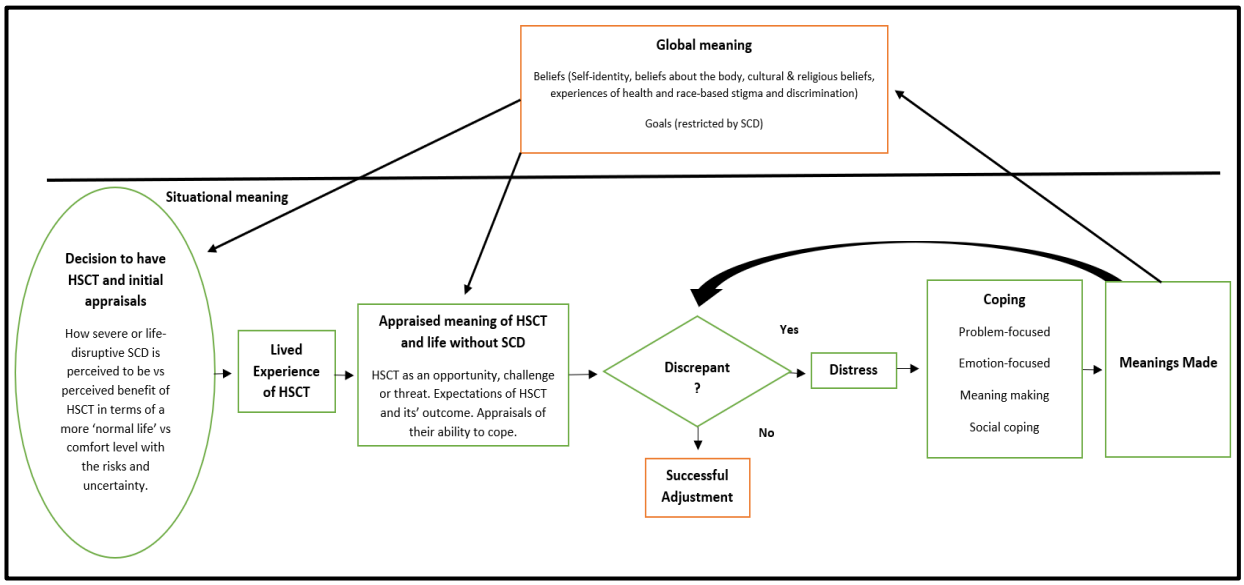
The predominant emotional tone here appeared to convey a sense of sadness and regret, rather than frustration, yet in addition to the personal losses to himself, he also made the economic point that HSCT for SCD is ultimately a cost saving for the NHS, a persuasive part of the argument that eventually resulted in it being funded by NHS England.

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter, the results of the IPA analysis will be discussed, with these being compared to the literature on HSCT for SCD and Crystal Park's meaning-making model. While other theoretical models were considered, most notably the Social Cognitive Transition (SCT) model of Adjustment (Brennan, 2001), for me, Park's meaning-making model provided the most coherent way of understanding the accounts given by participants and shared a strong similarity with IPA's concern with meaning-making, as well as being highly consistent with a Counselling Psychology perspective. It also fits with the conclusions of Gallo et al. (2019a), that recipients' beliefs, goals and sense of purpose guided the interpretation of their HSCT experience. An outline of how this model might be adapted is presented is provided in figure 3, which I will refer back to throughout this discussion.

Figure 3. Park's Meaning-Making Model adapted for HSCT for SCD



Reference will also be made to the aims and objectives of the research, namely, what can be learned in relation to the provision of psychological therapies, as well as limitations and suggestions for future research. Finally, a section on reflexivity will consider my role in the research process and the impact it has had upon me.

5.2 Leaving the Inferno

In relation to the meaning-making model of Park, the literature has only discussed the application of this model in circumstances where a person has experienced an unwanted life event, such as an illness, injury, or stressful or traumatic event (Park, 2013; Claudio et al., 2016; Park, 2010; Park & Kennedy, 2017). The model has not been discussed in relation to a

situation where the person consciously chooses to have the experience, though it does seem it can be usefully applied to HSCT for SCD with some minor modifications. In deciding to proceed with the transplant, participants appeared to be appraising the transplant primarily in a positive way, as a challenging but potentially life transforming opportunity, in contrast to viewing it as a threat as people having HSCT for cancers often do (Baliousis et al. 2016). This is a stage before the actual lived experience of HSCT, where appraisals were subject to continuous revision depending on what happened to the recipient.

The meaning-making model can also help in conceptualising how the decision to have the transplant will inevitably be made in relation to global meanings developed in the context of having lived their entire lives with SCD. Participants' accounts of their lives before the transplant corresponded closely to the literature summarised earlier, which points to the very detrimental impact of SCD upon Health-Related Quality of Life (McClish et al., 2005; Anie et al., 2002). Given that HSCT is only provided for people with severe SCD with complications, this finding is not surprising (NHS England, 2019a). The disruption caused by frequent episodes of ill health and hospital admissions had far-reaching consequences upon all areas of participants' lives, similar to those reported by HSCT recipients in the studies by Bruce et al. (2022) and Dovern et al. (2023). Participants in the current study also spoke of the negative psychological impact of SCD, which corresponds to the lives pre-HSCT described by recipients in the Bruce et al. (2022) and Dovern et al. (2023) study, who spoke of feeling insecure, lonely, depressed, anxious and stressed due to SCD and its unpredictability.

Studies suggest that attitudes of people with SCD towards transplants vary, ranging from unfavourable to favourable, with serious decisional dilemma being expressed (Bakshi et al., 2020). In a study by Meier et al. (2015), while the majority of people with SCD said they would be willing to accept the risk of HSCT-associated mortality, GVHD, or infertility, a significant number were not. In judging the potential benefits and risks of the transplant, the process most participants described in the current study maps well onto the personal risk-benefit analyses undertaken by participants in a qualitative study by Cho et al. (2020), which consisted of 2 major factors:

(1) how severe or life-disruptive they perceived their SCD to be; and
(2) their comfort level with the risks and uncertainty.

In that study, the twenty participants who proceeded with HSCT or gene therapy cited the intolerability of their current SCD symptoms and/or hope for a better future without SCD as being strong influences, while the six decliners thought the risks were not worth the potential benefits as their SCD was relatively mild. All the participants in this current study cited the

worsening of SCD over time and progression of disease-related complications as major reasons they decided to proceed with HSCT. Its hoped-for benefits were the chance of a better future and more normal life unhindered by SCD. Similar reasons were given by recipients in the Khemani et al. (2018) and Gallo et al. (2019b) studies, with HSCT being seen as a 'cure' and chance to live a longer, healthier life, while in a recent qualitative study by Mekelenkamp et al. (2024), "hoping for a normal life" was an overarching theme in the HSCT decision-making process of the caregivers (in the case of children) and patients with SCD and other hemoglobinopathies.

Most participants in the current study emphasised that deciding to proceed with HSCT had been a personal choice, and while the views of family were considered by some, none described having felt pressured. This was similar to the participants in the Cho et al. (2020) study, who described their decision to proceed as their own despite the influence of family and friends, but contrasts with the experiences of some of the recipients in the studies by Gallo et al. (2019a) and Gallo et al. (2019b), who spoke of the influence and at times pressure to go ahead with the transplant they experienced from family and health providers, not feeling they had sufficient time to consider their decision.

In terms of their comfort level with the risks and uncertainty of HSCT, a number of participants spoke of knowing straight away they would go ahead with it and not being concerned about the risks, or of purposely avoiding thinking too much about them, though they did express having some worries about acquiring additional complications. Only two participants, Femi and Samuel, described having carefully deliberated about whether to proceed or not, and said this had been a difficult decision, though Samuel did report he purposely didn't overthink the risks, being aware this could tip into worry and rumination which may have resulted in him not going ahead with the transplant.

When adjusting to life after the transplant, some participants reflected that in retrospect, they'd minimised the significance of HSCT and the seriousness of the decision they'd made in having it. This is likely to reflect common cognitive biases toward positive pieces of information and avoidance of thinking too much about negative outcomes which operated at the time of making the decision. This could have included heuristics such as an optimism bias, where they perceived the likelihood of positive outcomes as higher than the actual probabilities (Ozdemir & Finkelstein, 2018), and the planning fallacy, reflecting a tendency to underestimate the time and personal costs of what was involved (Kahneman, 2011). Further support for the role of cognitive biases comes from some of the participants in the Cho et al. (2020) study, who acknowledged that they might have forgotten, selectively heard,

or misremembered information provided about potential complications of HSCT and the possibility of ongoing SCD symptoms.

Mekelenkamp et al. (2021) classify HSCT for SCD as being a complex preference-sensitive decision, wherein no clear-cut answers are available and the pros and cons are dependent on individual values. They propose that shared decision making (SDM) is a fitting approach to adopt in such cases. SDM is a collaborative process through which a clinician supports a patient to reach a decision about their treatment by sharing their expertise and information (such as treatment evidence, risks and benefits), actively inviting patients to deliberate about options, while eliciting and exploring their preferences, before finally the decision is made based on the patient's personal circumstances, goals, values and beliefs (NHS England, 2019b).

The link to conducting a pre-transplant psychological assessment seems particularly relevant here. Whilst none of the participants in the current study spoke in detail about the experience of having engaged in one themselves, it does appear to be important that potential recipients are given an additional opportunity to weigh up the potential risks and benefits, in order to ensure they have a clear understanding of the HSCT process. This can help them be realistic in their expectations, such as recognising and accepting that the transplant will not usually undo complications caused by SCD, such as chronic pain and organ damage (Lagerdahl et al., 2024; Mekelenkamp et al., 2024). This would reduce the chances of recipients feeling like they were not sufficiently prepared for the side effects and complications they could experience, as was unfortunately reported by some of the participants in the studies by Gallo et al. (2019b) and Hastings et al. (2019).

5.3 Travelling through Purgatorio

As we saw earlier, studies of people having HSCT predominantly to cure blood cancers have found that a high prevalence of psychological distress is reported (Amonoo et al. 2019), particularly during hospitalisation, with psychological distress generally improving following transplantation, though persisting for a year afterwards for 30-40% of recipients (Mosher et al., 2009; Baliousis et al., 2016). In contrast, in the current study, hospitalisation wasn't described as the worst part of the treatment by most participants. This may be related to the lower intensity conditioning they underwent, which would be expected to have resulted in fewer unpleasant side effects than seen when HSCT is used for cancers (Cimpeanu et al., 2021). It also appeared participants' familiarity with being in hospital and a lifetime of

experience in dealing with ill health resulted in greater levels of self-efficacy and secondary appraisals of their perceived ability to cope with this part of the HSCT process.

The time after the transplant, in contrast, was cited as more difficult, with participants in the current study encountering unfamiliar and challenging experiences. Discrepancies between expectations and actual lived experiences became apparent, in particular around the length of time recovery took and the need to be on immunosuppressants for longer than they'd anticipated. As such, their appraisals, which are the central drivers of coping and adjustment (Lazarus & Folkman, 1984), were updated. For Joseph and Samuel, who both became very unwell, this appeared to result in temporary reappraisals of the HSCT process as being a threat which could result in death or lasting complications. This is consistent with the conclusion of Baliousis et al. in their 2016 systematic review, that viewing HSCT as a threat was a predictor of distress.

Following the transplant, estimations of self-efficacy and confidence in being able to cope also seemed to reduce for a number of participants, which Baliousis et al. (2016) identified as another predictor of distress during HSCT. The newness of the procedure and uncertainty about the outcome all seemed to have an effect, and some participants spoke of realising what a significant event HSCT was, which resulted in reappraisals of it being more challenging and potentially threatening than expected. The need to restrict social activities to avoid infections was something one of the more active and extraverted participants found challenging and was something participants in the Dovern et al. (2023) study struggled with as well.

Coping is defined by Lazarus and Folkman (1984) as 'the constantly changing cognitive and behavioural efforts to manage the specific external or internal demands that are appraised as taxing or exceeding the resources of the person'. Participants' ways of coping with the demanding experiences of HSCT varied. **Problem-focused coping**, which entails taking direct action to change external conditions (Lazarus & Folkman, 1984), was not amenable, as undergoing HSCT is a low control situation where there was little that participants could actively do other than to adhere to medications, attend appointments, and follow the recommendations to self-isolate while immunosuppressed.

Emotion-focused coping, employed by a number of participants, is centred around trying to directly alleviate distress through strategies such as distraction and avoidance (Lazarus & Folkman, 1984). In the Khemani et al. (2018) study, distraction was also commonly used as a coping strategy, though of note, avoidance coping was a predictor of distress in HSCT identified by Baliousis et al. (2016) and also of increased interference from common cancer

symptoms six months after HSCT in a study by Schoulte et al. (2011). It may be most helpful to view avoidant coping as one form of emotion-focused coping, and one that can be usefully employed to reduce the intensity of the distress in the short-term and thereby facilitate adjustment (Brennan, 2018), but which is not helpful if used for prolonged periods of time.

Meaning-making coping refers to the processes people engage in to reduce the discrepancy between appraised meaning and global beliefs and goals (Park, 2010). This form of coping was employed by participants at various points in their transplant journey, which is considered potentially more adaptive in low-control situations (Park, 2010). As reported earlier, in relation to HSCT for haematological malignancies, Adelstein et al. (2014) concluded those patients who found meaning in their experience were better able to manage their physical symptoms and were less likely to report psychological morbidity than those who struggled to find meaning in their experience.

In the current study, meaning-making was used in coping with challenging experiences such as getting sick, having graft versus host disease and being socially isolated, and at this point such processes focused on changing the appraised meaning of the situation, rather than global meanings. This seemed to take two key forms:

1. Reminding themselves that the unpleasant and arduous experiences they were having was something they needed to temporarily endure in order to be free of SCD. This entailed thinking of the future and the hoped-for benefits HSCT would bring.
2. Comparing their current difficult experiences to those they'd gone through in the past when having a sickle cell crisis and reminding themselves how bad these had been.

Finally, **social coping** (Algorani & Gupta, 2023) was mentioned by all participants in relation to the support they received from family and friends. This was emphasised most by the two participants from Africa who also had the least favorable attitudes towards the offer of psychological therapy and declined it.

While the classification of these coping styles implies a neat separation between them, in reality there can be considerable overlap, and much depends on the context and way they are employed. For example, the use of positive thinking described by Chima could be seen as a form of avoidant coping if used primarily as a means of experiential avoidance (Hayes et al., 2012) to escape from difficult emotions, or a form of meaning-making if used to appraise and make sense of difficult experiences by holding in mind hoped for outcomes. Strategies such as prayer and maintaining a positive attitude, which were reported as coping strategies

in the study by Khemani et al. (2018), could also be categorised as meaning-making focused or emotion-focused coping depending on the context and way they are used.

Previous studies have demonstrated such classifications are unstable and depend on the type of stressful situation encountered and sample investigated (Aldwin, 2007). More important perhaps is the classification of coping strategies as being adaptive or maladaptive depending on different factors. Forms of coping that have been shown to promote adaptive outcomes include problem-focused strategies if the stressor is controllable, emotion-focused strategies if the stressor seems uncontrollable, meaning-focused coping, and actively seeking social and emotional support from others (Aldwin, 2007; Park et al., 2008). Rigid avoidant strategies are generally considered maladaptive, and include substance use, social isolation, and prolonged emotional suppression (Compas et al., 2017; Connor-Smith & Flachsbart, 2007; Park et al., 2012). Rumination has also been associated with psychological disturbance and maladaptive adjustment (Nolen-Hoeksema et al., 2008).

Judging if a coping strategy is helpful or not is ultimately based on whether it results in higher levels of resilience and consistent adjustment over time (Galatzer-Levy et al., 2018), and importantly, by the person undergoing HSCT themselves. For example, the use of positive thinking by Chima seemed to increase his perceived self-efficacy by focusing on what he felt to be within his locus of control, namely his inner thoughts and feelings, rather than what was outside his control, which was what was happening to his body and the overall HSCT process. In this context therefore it can justifiably be classified as an adaptive coping style. Exploring the origins, function and effect of such coping strategies, as well as considering alternative strategies, is something that could be done within psychological therapy if this were available to recipients and something with which they were willing to engage.

5.4 Journeying towards Paradiso

As reviewed earlier, several studies have reported improvements in Health-Related Quality of Life (HRQOL) following HSCT, though long-term complications caused by SCD continued to impact on physical functioning (Saraf et al., 2016; Gallo et al. 2019a; Badawy et al., 2020). Such studies have also shown changes in recipients' life goals. Of the previous studies that adopted qualitative methods, only that by Dovern et al. (2023) contained details of the psychological adjustment recipients were required to make in transitioning to a life without SCD.

In the current study, the process of adjustment was an important theme. With reference to the typology of levels of meaning presented by Smith (2018), participants were not only

trying to make sense of the meaning and significance of the transplant at an experiential level, but also what it meant at an existential level, in relation to their identity. A major adjustment most participants spoke about was in relation to their bodily experience and continued anticipation that doing certain activities would still result in them having a sickle cell crisis. This resonated with experiences reported by recipients of HSCT in the Dovern et al. (2023) study, who struggled to emotionally process and adjust to not having SCD anymore, at first anticipating still getting sick and having a sickle cell crisis in certain situations, and sticking to patterns of behaviour established from years of living with SCD.

In relation to Park's meaning-making model (2010), this adjustment would appear to require changes at the level of **global meaning**, including **global beliefs** about their bodies no longer being so vulnerable, and them now being capable of doing a wider range of things. This was a process of meaning-making that had yet to be completed by most participants at the time they were interviewed, with them reporting that engaging in previously avoided activities triggered assumptions developed over years of living with SCD that the body would experience pain. Having lived with SCD all their lives, participants' sense of identity seemed intrinsically connected to their bodily experiences.

Other aspects of changed identity spoken about by some participants in the present study were about how they thought of themselves now in relation to SCD and to other people, which again suggests changes occurring within global meanings. For some participants, this process of meaning-making was ongoing, with Ola and Samuel still figuring out who they were without SCD and trying to reconstruct their identities to accommodate this change. In contrast, Amara seemed to have made meaning by conceptualising herself as someone with sickle cell trait, which appears to have contributed to her adjustment by integrating the experience into her identity.

In relation to the impact of the transplant, two participants in the current study spoke very enthusiastically about the benefits they'd experienced and the new activities and goals they were pursuing that were not attainable whilst living with SCD, which in relation to Park's meaning-making model, would entail changed **global goals**. Park and Folkman (1997) report that many studies support the idea that making positive reappraisals of events is associated with good adjustment, and is therefore an adaptive strategy. The positive impact of the transplant, despite some disappointments, was a strong theme identified in the majority of previous studies into HSCT for SCD, as was the ability to engage in activities and pursue goals they'd previously been unable to do (Khemani et al., 2018; Gallo et al., 2019a; Hastings et al., 2019; Abu al Hamayel et al., 2021; Bruce et al., 2022).

The remaining four participants in the current study were more cautious in their assessments of its impact, which appeared related to the following factors:

1. **Complications caused by SCD:** One of these participants continued to experience severe impacts of SCD, which restricted what he could do.
2. **Having been very unwell or experienced complications associated with HSCT:** One of the participants had experienced GVHD, one had become very unwell soon after the transplant, and one had picked up two serious infections while immunosuppressed. Unsurprisingly, the two participants who were more positive about the impact of HSCT did not report experiencing any serious adverse effects.

The duration of time that had passed since participants had received their transplant may also have been a factor, since the two who were most positive about its impact had theirs 19 and 20 months previously and were further along their journey than three of those who were more measured in their assessments, who had theirs at 10, 14 and 16 months earlier. In the Bruce et al. (2022) study, quality of life was unsatisfactory during the period of time recipients were hospitalised and the months after, but there were clear improvements at one-year post HSCT. While for recipients in the Abu al Hamayel et al. (2021) study it took up to two years for pain to resolve entirely post HSCT, which delayed their ability to pursue activities that had positive effects on their physical and mental health, such as re-enrolling in school, finding work, and exercising regularly.

It can therefore be speculated that appraisals of the impact of HSCT could become more positive over time for participants in the current study as they continue to adjust and move towards a more 'normal life', assuming they do not encounter any further complications or their transplants were to fail. Indeed, three of them said they thought in the future they would set themselves bigger goals and plans when they'd had more time to adjust and felt more confidence the transplant had been successful. They therefore seemed to be still in a process of making sense of how HSCT could alter their global goals, which resemblances the experiences of recipients in the Dovern et al. (2023) study, who found themselves overwhelmed when confronted with a new and unfamiliar reality without SCD, to which they needed time to adjust. Also of note, perceptions of growth were spoken about by Samuel, and to a greater extent Ola, who described changes in her whole outlook on life, with her becoming less self-conscious and more appreciative of things. Such changes are frequently cited as a feature of stress or trauma-related growth, associated with changes in global meaning (Park 2010).

For some participants there seemed to be a continuation of the process of reappraising HSCT, with some reflecting that in retrospect, they'd minimised its significance and the seriousness of the decision they'd made in having it. It is noteworthy that as in all the previous studies reviewed, none of the recipients' expressed any regrets about undergoing the transplant despite the difficulties and complications, which could be seen as part of the same process of reframing the experience of HSCT to make it meaningful as described in the studies by Gallo et al. (2019b) and Hastings et al. (2019). It may also reflect the operation of a confirmation bias (Kahneman, 2011), as recipients search for evidence that supports their decision to have the transplant. It is important to highlight as well there may have been a bias in the sample, with those choosing to participate in the study being those who did not regret having HSCT, and those who did have regrets not wishing to participate.

5.5 Implications for the role of psychological therapy during HSCT for SCD

As we have seen, attitudes towards psychological support varied in the current study, which seemed partly related to different coping styles adopted by participants and potential cultural factors. As reported earlier, in the Dovern et al. (2023) study, recipients expressed the need for psychological help in relation to the mental impact of having SCD their whole life, as well as to help emotionally and mentally process the impact of HSCT. The following section will therefore draw some conclusions about the role of psychological therapy throughout the HSCT process and in supporting recipients in adjusting to a life without SCD.

5.5.1 The potential benefit of psychological therapies to support meaning-making and adjustment

In the current study, two of the participants who did engage with psychological therapy described the ways it had helped them. Samuel appeared to use personal therapy to assist with the ongoing process of meaning-making, describing it as helping him in piecing things together, figuring things out and learning how to live without SCD. Femi meanwhile, cited strategies such as taking a longer-term perspective as having been helpful, alongside other practices. Given that most participants described undergoing a process of meaning-making and adjustment, psychological approaches that support with this would seem particularly relevant. This is especially the case given that where people struggle unsuccessfully to reconcile the appraised meaning of their experiences with their global beliefs, values and goals, this can result in them getting suck in continuing reappraisals in a ruminative process (Park & Folkman, 1997).

As discussed earlier, Baliousis et al. (2016) concluded a potential, albeit small, benefit of psychological interventions for distress in HSCT, particularly for those incorporating a major psychological component such as CBT or emotional processing. CBT is a broad family of different therapy types, however, and the style in which it is employed is also important in terms of potentially helping people with SCD undergoing HSCT. For example, Cognitive Therapy can be applied in a highly protocol-driven way, using language such as cognitive errors or distortions (Beck, 1995). This is less likely to be as good a match than if applied in a more flexible way, examining the way core beliefs and assumptions are interacting with meaning-making of the experience of HSCT and adjusting to life without SCD, evaluating and restructuring these where required, facilitating the processing of emotions (Power & Dalgleish, 1997; 1999) and experimenting with new behaviours to see how they fit with their changed circumstances (e.g. Moorey, 1996).

Rather than focusing primarily on alleviating distress or thinking more realistically, as in traditional forms of CBT, 'third wave' CBT approaches may be more suitable. One such form is acceptance and commitment therapy (ACT), which has an increasing evidence base in improving quality of life and psychological wellbeing in a range of long-term health conditions (Hayes, 2019; McCracken et al., 2022; Gould et al., 2024). Its central model of psychological flexibility, pragmatic and non-pathologising stance, and emphasis on finding meaning through the clarification of a person's values, would appear potentially beneficial to people with SCD going through HSCT and adjusting to life afterwards.

For recipients in the Abu al Hamayel et al. (2021) study, pain took up to two years to resolve entirely post HSCT, and some participants in the current study described still anticipating pain, with their bodies having to undergo 'reprogramming' to dampen down the sensitisation and learning that had occurred as a result of repeated episodes of sickle cell pain over many years. In their review of 25 randomized controlled trials of ACT for adults with chronic pain, McCracken et al. (2022), found small to large effect sizes for key outcomes including pain interference, disability, depression, and quality of life. ACT would therefore also seem helpful in supporting people with SCD to live alongside any continued pain they experience after HSCT and in weaning themselves off opioids, which is important given that having such support from the healthcare team was associated with the most successful and positive experiences in the Abu al Hamayel et al. (2021) study.

As an alternative to the dominance of CBT approaches, the existential-phenomenological tradition's emphasis on meaning-making appears highly applicable to people with SCD undergoing HSCT. Cooper (2017) informs us that existential philosophy and therapy takes as

its primary concern human lived-existence and has been translated into various therapeutic approaches, such as Viktor Frankl's (1905 – 1997) *Logotherapy*, which continues to be a major influence on meaning-centred approaches to therapy (Cooper, 2017). There is solid evidence of meaning-centred approaches being effective with people experiencing chronic or life-threatening diseases (Vos, 2016), while the integrative literature review of HSCTs for haematologic malignancies conducted by Adelstein et al. (2014) concluded that interventions designed to promote meaning-making would be beneficial to patients undergoing a HSCT. There are a variety of therapeutic methods that can be employed to assist people with SCD who have undergone HSCT in the process of meaning-making, such as those presented by Voss (2016).

The ideas of Maurice Merleau-Ponty (1908-1961) also appear important. In Merleau-Ponty's view, a person does not just possess a body, but they *are* their body, and he emphasised the embodied nature of our *being-in-the-world*. Merleau-Ponty made a distinction between the 'objective body' as a physiological entity, and the 'lived body' (*Leib*), which refers not only to the felt, subjective experience of bodily sensations, but also to the way we act, perceive and exist through the body without explicitly reflecting on this (Morris, 2008; Finlay, 2011). In relation to this physical (unwelt) dimension (van Deurzen & Arnold-Baker, 2005), the facticity of existence for a person with SCD involved being born into a body that shaped the fundamental character of their experience of the world by creating experiences of pain, fatigue, and the possibility of premature death. Scores on HRQOL questionnaires such as the SF-36, that focus on the 'objective body' as a physiological and anatomical entity, cannot capture the enormity of the changes which HSCT recipients went through in their subjective 'lived-body'. The ideas of Merleau-Ponty could help in gently exploring how recipients now subjectively experience being in their bodies, reflecting on both the new feelings and sensations, and, as in Samuel's words, on the bodily effects of 'the legacy of having lived a life with SCD'. This could facilitate the process of becoming 'reacquainted' with the body, updating global meanings, and adopting new embodied ways of *being-in-the-world*.

5.5.2 The relevance of culturally sensitive therapy and African psychology

All six participants in the current study were Black, with two being born in African countries before coming to England in their teenage years and the remaining four being born in England. The two participants who grew up in Africa expressed the least favourable attitudes towards psychological therapy. As we have discussed, people with SCD are almost exclusively from a racial and ethnic group who are under-represented in IAPT services (NHS Race and

Health Observatory, 2023), and mistrust of statutory mental health services is likely to be an important barrier to accessing therapy (Project, 2023). Due to the economic challenges frequently faced by people with SCD (Dyson, 2019), accessing therapy privately or via private health insurance is also unlikely to be an option for the majority of them going through HSCT. It is therefore most likely if recipients of HSCT with SCD do access psychological therapy, this will be offered by the transplant centre itself, or through a psychology service provided by their local haematology service, though the availability of these services is varied (WMQRS, 2016; Naidoo et al., 2022).

One of the multiple aims of the pre-transplant psychological assessment is to 'familiarise patients with psychology services so that these may be perceived as a normal part of routine care and a helping relationship can be established in a timely way' (Lagerdahl et al., 2024). One consideration is who is offering this to HSCT recipients. There remains a serious shortage of Black psychologists (McInnis, 2021), and within IAPT it's estimated only 5% of staff are Black or Black British, with the vast majority being White and female (approximately 80%). This can affect engagement and uptake of treatment, particularly for men from Black and ethnic backgrounds (NHS Race & Health Observatory, 2023). While the diversity of psychologists and psychological therapists working in transplant centres is unknown, it seems reasonable to assume the percentages are similar, especially based on my experiences of being part of the BPS Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia and joining meetings of the Stem Cell Transplant Psychological Professionals Network (SCTPPN). At this point in time, it is therefore unlikely HSCT recipients with SCD will be matched with a therapist similar to them in race and ethnicity.

Psychologists and psychological therapists can mitigate some of these barriers by striving to make psychological assessments and therapy culturally sensitive (Naeem et al., 2023), considering any 'attitudes, feelings, experiences or circumstances that may be common to the person's racial, national, religious, linguistic or cultural background' (NHS Race & Health Observatory, 2023). It would appear essential they adopt an intersectional position and also have knowledge of the health inequalities, stigma, racism and discrimination experienced by people with SCD, developing a degree of sensitivity and confidence in asking about such experiences (Ade-Serrano & Nkansa-Dwamena, 2016; Nkansa-Dwamena, 2017). Importantly, the NHS Race & Health Observatory report 'Ethnic inequalities in improving access to psychological therapies' (2023) noted poor outcomes can be tackled and even disappear when access is improved and culturally sensitive therapy is provided. Interestingly, people from Black African backgrounds using IAPT services were sometimes actually more likely to improve and recover in comparison with White British people.

In relation to which psychological therapies are offered, CBT remains the most dominant model used by NHS psychology services, an approach which can be perceived as Eurocentric (Naeem et al., 2019; NHS Race & Health Observatory, 2023) and not promoting wellness and resilience effectively enough in those of African heritage (McInnis, 2018). Approaches derived from African Psychology may be more palatable to many people with SCD undergoing HSCT. Also known as Black Psychology, Africana Psychology, or African centred, Karenga (2010) defines African Psychology as being 'An ongoing synthesis of the best of African culture, values, thoughts and practice in constant exchange with the real world'. African psychology is non-deficit-based and promotes thriving, and Cokley & Garba (2018) and Bethea (2020) comment on the similarities it shares with Positive Psychology, with the identification of characteristics utilized in coping and in flourishing. McInnis (2018) emphasises Black psychology is not a rejection of Eurocentric psychology, rather "it's about advancing a science of human functioning for black people around the world, using the best of African thought, culture and rituals to create wellbeing". This can include reflecting on stories, proverbs and sayings familiar to particular families or communities, which represent strategies for dealing with life situations and traditional wisdom (McInnis, 2021).

African Psychology also has a focus on the person's spiritual needs, which is important, as the Black British Voices Project (Project, 2023) highlighted how faith matters more for Black communities than the British population as a whole, with 84% of participants self-described as religious or spiritual. Christianity was the most popular faith, followed by Islam and Rastafarianism in second and third places. A literature review by Clayton-Jones & Haglund (2016) highlighted how spirituality and religiosity may ease the burden faced by persons living with SCD and be a strong source of coping, while in the Gallo et al. (2019a) study, seven recipients described having a strong faith-based system which they drew upon to interpret their HSCT experience. In this study, Chima emphasised the importance of his Christian faith. NHS Chaplaincy services may therefore play an important role in providing spiritual, pastoral and religious care to people with SCD having HSCT during their hospital admission (NHS England, 2016; 2023).

The degree to which ideas and practices from African Psychology can be drawn upon by psychologists and psychotherapists who themselves are not Black or from an African background is a contentious topic, and accusations of cultural appropriation could certainly be justified if not done in a very sensitive and reflective way. McInnis (2018), however, makes the pragmatic point that there simply aren't enough Black psychologists currently to address the issues raised by African Psychology, and certainly there are not sufficient Black psychologists and psychological therapists within transplant centres to provide racial and

ethnic matching for people with SCD undergoing HSCT. African Psychology can perhaps be most effectively used at this point in time to assist therapists in reflecting on the impact of their own culture, prejudices, ethnocentrism and stereotypes (Eleftheriadou, 2010), and enhancing their sensitivity, understanding and responsiveness to what people with SCD may need from therapy.

Finally, while race and culture haven't been explicitly discussed in relation to Park's meaning-making model, at the global meaning level it would appear the model can accommodate details of important historical, racial and cultural factors that will influence and interact with how people respond to significant life events, such as HSCT. There are also several papers and books which have explicitly considered this model in relation to spirituality and religion (Park, 2013; 2020; Park et al., 2017), which have some transferability for how it might be applied.

5.5.3 A Counselling Psychology perspective

Counselling Psychology offers one means of bringing together the various approaches to providing psychological therapy to people with SCD undergoing HSCT, though these methods are also available to other psychologists and psychological therapists. Firstly, Counselling Psychology's embrace of a dialogical and pluralistic stance with regards to practice could allow for the introduction of an African Psychology perspective into therapy as a challenge to the Eurocentric models and values which are often an 'unquestioned given' (BPS, 2019; BPS, 2021), while holding tensions between such conflicting theoretical paradigms in a constructive dialogue, rather than trying to resolve them (Orlans & Van Scoyoc, 2009; Manafi, 2010).

An emphasis on collaboration and metatherapeutic communication about what the client wants from therapy and how this can be achieved, can be a powerful means of enhancing the fit of the therapy to the individual client (Cooper et al., 2016). It also offers a way of selecting and introducing ideas and methods from African psychology and other approaches as options based on the available evidence of what may be helpful to people with SCD undergoing HSCT (Cooper & McLeod, 2007; Hanley et al. 2017), such as those discussed earlier from CBT, ACT, existential, and meaning-centred therapies.

Secondly, the application of the humanistic value-base as a core feature of Counselling Psychology (BPS, 2019), which Cooper (2009) extends to Levinas's (1969) notion of 'welcoming the Other' and honouring them 'in all their otherness', would allow for an understanding of the experience of HSCT from the recipient's unique frame of reference,

with a holistic and developmental view of how it fits within the context of the physical, social, cultural, and spiritual dimensions of their entire life (BPS, 2005; Manafi, 2010; Kasket, 2017). Counselling Psychology's commitment to relational ways of working (Frankland, 2017; BPS, 2019;) would also place more of an emphasis on '*Being-with'* HSCT recipients empathically and unconditionally while they make sense of their experiences, rather than focusing upon intervening or doing something to them (Strawbridge & Woolfe, 2003).

Thirdly, Counselling Psychology's focus on wellness and optimal functioning (Strawbridge & Woolfe, 2010; James, 2018) can open up a space to talk to HSCT recipients about their own strengths and resources, which for people with SCD could include spirituality, religiosity, and aspects of African thought and culture, and explore how these can contribute to the alleviation of difficulties and in promoting thriving and flourishing (Cooper & McLeod, 2011). Within hospital settings, this could include linking them into NHS chaplaincy services (NHS England, 2023).

Finally, a Counselling Psychology perspective can assist in placing an emphasis on a relational approach to supporting people with SCD through HSCT at the level of the Multi-Disciplinary Team and indeed the healthcare system as a whole (Costa-Cordella & Luyten, 2024). Teaching and promoting psychological mindedness and skills in other health professionals can assist them in applying the six principles of Trauma-Informed Care (safety, trust, choice, collaboration, empowerment and cultural consideration), which are essential in integrating an understanding of an individual's developmental history, past trauma, and current relational dynamics into healthcare interactions (SAMHSA, 2014; Office for Health Improvement & Disparities, 2022). This is especially important given the unhelpful interactions with health professionals and discrimination and trauma people with SCD may well have experienced (Sickle Cell Society, 2021). By working systemically with healthcare staff, Counselling Psychologists can play a vital role in extending Trauma-Informed Care beyond the aim of avoiding re-traumatization, towards actively building genuine trust with adults with SCD and promoting their health.

5.6 Strengths and limitations

Caution needs to be exercised in making generalisations about the experience of HSCT for adults with SCD, as the number of participants in this study were small. Six is considered an appropriate number for an IPA study, however, and at the point of completing my interviews, it was estimated only 14 adults with SCD had completed HSCT on the NHS in England, so this study succeeded in capturing the lived experiences of nearly half of these people (S.

Chakravorty, personal communication, Nov 16, 2023). Additionally, by synthesising the seven previous studies into HSCT for SCD that included qualitative methods and incorporating this into the discussion section, a wider range of experiences have been drawn upon in considering the implications for psychological therapy provided. In the recent study by Mekelenkamp et al. (2024), almost all patients and parents expressed a wish for peer contact with people who had already undergone an HSCT to enrich their knowledge and to prepare them for it. As the number of HSCT recipients are currently so small in England, providing peer contact is difficult, and so this study provides a way to compensate for this by giving access to in-depth accounts of the lived experience of HSCT from adults with SCD.

This study has been different from previous studies by adopting IPA as a methodology and having an explicitly psychological focus, with the aim of collecting rich and detailed accounts of the experience of HSCT which could contribute to an understanding of how recipients can be supported psychologically through this major life transition. While in most of the previous qualitative studies into HSCT for SCD, recipients reported changes in their educational, occupational, leisure and social roles, none of these studies explicitly detailed changes in identity and the process of adjustment, with the exception of the Dovern et al. (2023) study. This is more likely related to the questions asked in the interview schedules and the methodologies used, rather than these themes being absent from the recipients' lived experiences. The current study also addressed a significant gap in the research, with no prior qualitative studies having taken place including SCD recipients of HSCT in England, and no Counselling Psychology studies carried out in relation to SCD.

A limitation is that there was a degree of heterogeneity in the sample. For instance, the time since transplant varied between participants, which meant they were at somewhat different points in their recovery and journey. They also varied in having had their transplants at different hospitals, and one of the participants was still struggling physically with the long-term impact of a stroke, which in his words meant the impact of the transplant was not what it might have been. Despite this heterogeneity, there were strong areas of convergence in the accounts given of the experience of HSCT. As mentioned earlier, there may have been a bias in the sample, with those choosing to participate in this study being those who did not regret having HSCT, and those with quite different lived experiences and regrets not wishing to participate.

5.7 Future research

Longitudinal IPA studies (Smith et al., 2022; Smith & Nizza, 2023) would appear particularly suited to investigating this topic in the future, where interviews could be conducted at different time points with the same participants to capture how the experience of HSCT and adjusting to life without SCD evolves over time and reducing the risk of recall biases. Such time points could be pretransplant, a year afterwards, and ideally at longer and longer time intervals afterwards. Longitudinal designs were used to good effect in the studies by Bruce et al. (2022) and Dovern et al. (2023), and future IPA studies could focus on different aspects of the process, such as how recipients' sense of identity and relationship with their body changes over time.

Mixed-methods designs, where IPA is combined with quantitative methods (Smith et al., 2022), would also be valuable to understand the relationship between the recipients' experience of the *process* of undergoing HSCT, and various ways of understanding the *outcome* of HSCT, such as questionnaires (to assess quality of life, pain, adjustment) and medical markers (including perhaps the use of opioids post HSCT). This would be most practical within research studies, such as the current REDRESS randomised trial, which generate a larger pool of potential participants and where gaining NHS ethical approval could be more achievable. Finally, as the number of HSCT recipients increase over time, alternate qualitative methodologies could be employed, such as studies employing discursive forms of discourse analysis to investigate how individuals use language to talk about and construct meaning around concepts such as being 'cured' of SCD (Willig, 2013).

5.8 Conclusions

The introduction by the NHS in England of HSCT as a curative treatment for people with SCD is an important and welcome step towards reducing health inequalities and compensating for insufficient investment in sickle cell care over many years (Sickle Cell Society, 2021). By adopting IPA as a methodology, this study has provided insights into the lived experiences of recipients of HSCT and the significant psychological adjustment and meaning-making required afterwards as they transition to a life without SCD. Crystal Park's meaning-making model (2010) provided a coherent theoretical way of understanding how this adjustment required experiences to be assimilated and accommodated into global meanings (beliefs and life goals) developed through a life lived with SCD.

In keeping with my aspiration that this research would make a positive difference in the world, the data generated have been discussed in relation to psychological therapy offered

to people with SCD throughout their HSCT journey, with approaches that can assist with the meaning-making process being highlighted as particularly relevant. The need to ensure therapy is provided in a culturally sensitive way was emphasised, with African psychology being identified as an alternative paradigm to contrast with more Eurocentric models of therapy. The relevance of a Counselling Psychology approach was explored, especially in adopting a pluralistic and relational approach to providing therapy and in working with healthcare staff to extend the principles of Trauma-Informed Care to build genuine trust with people with SCD.

It is my hope that the conclusions derived from this study will be of relevance not only to psychologists and other psychological therapists, but also to other medical and nursing NHS professionals providing psychologically informed care, as well as to people with SCD considering HSCT or embarking upon this procedure. I also hope it sparks enthusiasm in readers to consider working with or undertaking research with this marginalized and neglected population.

5.9 Reflexive Conclusion

In completing this research thesis, I am left with both a great sense of achievement and also relief. While at times I questioned why I had embarked on such a demanding endeavor, especially as a Doctorate was not required for my employment within the NHS and I was already quite advanced in my career, as I'd hoped, for most of the time I felt extremely interested by the topic and stimulated learning how to do IPA and other aspects of the research process. I believe I benefited from a degree of maturity, having learnt from previous experiences the importance of being organized and strictly scheduling time to devote to it. While manageable, it did take a fair amount of grit and determination to complete, with it being mentally taxing to think about it so much and carve out the time required, while holding two NHS posts and remaining active in family life. Having never worked therapeutically with anyone who had gone through a transplant, my knowledge of what HSCT entails has been enormously enriched by undertaking this research, and I am now much more able to discuss this topic with people with SCD and contribute to meetings of the National Haemoglobinopathy Panel, where referrals for HSCT in England are discussed (NHS England, 2019a).

Two parts of the project were particularly challenging. Firstly, during the long recruitment phase I became increasingly worried about having to find a new topic for my research, or alter it considerably, as it became clearer that the number of HSCT recipients with SCD were

fewer than expected. Secondly, I found the analysis phase very demanding and felt quite overwhelmed by the vast volume of material I had to work with and the time I spent doing so was enormous. Mostly, I consider this to be an inevitable part of the task of gaining a thorough understanding of the analysis procedure and how it related to the theoretical underpinnings of IPA. It involved many false starts and was a highly iterative process which at times I felt could be never ending as I struggled to judge what was 'good enough'.

As a methodology, IPA continuously redirected me to reflect on how my preunderstandings could potentially open up or close down understandings. As I expected, HSCT was an event of considerable existential significance to recipients with implications for their sense of identity. I was surprised none of the participants spoke about feeling freed from the stigmatizing effects of having SCD. This expectation had been strengthened through reading the Bruce et al. (2022) study, where it was reported participants felt they had gained social acceptance from their extended families and communities who had previously stigmatized and excluded them. In retrospect, I think the study had quite a wide focus, so inevitably I could not explore all facets of the HSCT experience in depth. During the interviews I was aware of being cautious not to deviate too far from the interview schedule or for the interview to overrun, but as my understanding of IPA has developed, there are several occasions where I wish I had probed deeper and explored in more detail what a participant had said. If I were to repeat the study, I would be tempted to focus in on one aspect of the process of HSCT in depth, such as changes in identity or in embodied experience.

My observation that the two participants with the least favourable attitudes towards psychological therapy grew up in African countries prompted me to read further into African psychology and attend a workshop on this topic. This has resulted in me becoming even more conscious of my own Whiteness and keen to examine the ways in which the cultural attitudes I was exposed to growing up in England in the 1970s and 1980s may have shaped any implicit biases I hold in relation to Black people. While I had acknowledged this to a certain extent before, the 'invisibility' of whiteness makes it difficult to fully appreciate the unnoticed ways in which it defines norms and can contribute to systems of oppression and power which sustain racism (Ryde, 2011). Given the racial inequities within the healthcare system, this awareness is particularly important as I seek to adopt a social justice agenda (Cutts, 2013; Steffen & Hanley, 2013) and align myself ever more closely to an anti-racist stance (Patel, 2021). This is especially so as I contribute to discussions and plans within the NHS Trust where I work to improve services for people with SCD in line with the recommendations of the 'No One's Listening' report (Sickle Cell Society, 2021).

It has also led me to reflect on my role as a researcher, and the potential that my own Whiteness may have influenced the accounts participants shared with me, as well as how my own culturally informed interpretations could have closed down understandings. The legacy of the Tuskegee syphilis study is still widely recognized as a reason why many Black people are mistrustful of research because of the deception and mistreatment involved, though sadly this is by no means an isolated example (Scharff et al., 2010). The fact participants were informed about the current study by people they trusted from organisations such as the Sickle Cell Society and Anthony Nolen is likely to have been reassuring. Some participants also told me that part of their reason for agreeing to take part in the study was either because I was introduced to them as being someone who had worked with people with SCD for several years, or they knew of me already. This appeared to make me more trustworthy and credible to them as a researcher.

Finally, having been thoroughly immersed in IPA over the past two years, I can see how this methodology has had a discernible impact on how I carry out therapy, revitalising me with an increased focus on meaning and making me more likely to slow the pace of therapy and explore a person's subjective experience in much greater depth and detail. Thorpe (2013) makes the point that carrying out qualitative research can enhance skills that are central to therapy practice, such as empathic engagement and interpretation, and while my choosing of a qualitative approach and IPA in particular was partly influenced by the parallels this methodology has with the practice of Counselling Psychology (Kasket, 2016), it is immensely gratifying to see this as one of the most immediately tangible outcomes of having undertaken this Top-up Doctorate.

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Appendix 1) The transplantation process in SCD

What follows is a brief summary of HSCT for SCD.

Firstly, the donor's stem cells are 'mobilised' out of their bone marrow via an injection of a growth factor called G-CSF, which is given for four or five days. The stem cells then enter the blood stream and can be collected, or 'harvested', via a needle which is placed into a large vein in each of their arms. The stem cells are then processed to purify and concentrate them before they are frozen to preserve them. The recipient then undergoes reduced intensity conditioning by immunosuppressive medication and low dose radiotherapy for seven days to make physical space in their bone marrow for the donor stem cells, which are thawed and infused into their bloodstream through a central venous catheter. The recipient continues to be given an immunosuppressant medication and is hospitalized for approximately one month as the marrow begins to restore the immune system and produce normal red blood cells. During this time, they are kept in isolation in a side room to reduce the risk of infection.

After this, the recipient is usually able to go home, but will be monitored very closely and have one or two appointments a week in a transplant clinic before the frequency of these appointments decreases over time. It is recommended that recipients should take at least six months to a year off work or away from education, and restrict their social activities, due to their increased risk of getting an infection because of the immunosuppression medication they are required to continue to take. Side effects are often worse during the first 30 days and can include pain, fatigue, weakness, nausea, and disturbed sleep, though symptoms can also last more than a year after the transplant

Adapted from

Anthony Nolan (2021). The Seven Steps: The Next Steps. A handbook for long-term recovery after a stem cell transplant. Retrieved from: https://www.anthonynolan.org/sites/default/files/2021-08/1981PA_Next7Steps2021_DIGITAL.pdf

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https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-a-blood-disorder/sickle-cell-disease#risks-and-benefits

Appendix 2) Literature search

PsycINFO, final number of studies = 9

Search ID#	Search Terms	Search Options	Actions
S10	S5 OR S8	Limiters - Publication Year: 1984-2024; Document Type: Journal Article Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S9	S5 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S8	S6 AND S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S7	DE "Stem Cells"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S6	DE "Sickle Cell Disease"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S4	TI (qualitative or interview* or "case stud*" or "mixed method*") OR AB (qualitative or interview* or "case stud*" or "mixed method*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S3	TI (experience or psych* or "quality of life") OR AB (experience or psych* or "quality of life")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S2	TI ("haematopoietic stem cell transplant" or "stem cell" or transplant* or "bone marrow" or HSCT) OR AB ("haematopoietic stem cell transplant" or "stem cell" or transplant* or "bone marrow" or HSCT)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit
S1	TI ("sickle cell" or "sickle cell disease" or "sickle cell anaemia" or "sickle cell anemia") OR AB ("sickle cell" or "sickle cell disease" or "sickle cell anaemia" or "sickle cell anemia")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Rerun | View Details | Edit

CINAHL Complete, final number of studies = 112

Search ID#	Search Terms	Search Options	Actions
S10	S5 OR S8	Limiters - Publication Date: 19840101-20241231; Publication Type: Journal Article Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (112) | View Details | Edit
S9	S5 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (112) | View Details | Edit
S8	S6 AND S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (108) | View Details | Edit
S7	(MH "Hematopoietic Stem Cell Transplantation")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (10,393) | View Details | Edit
S6	(MH "Anemia, Sickle Cell")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (5,993) | View Details | Edit
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (10) | View Details | Edit
S4	TI (qualitative or interview* or "case stud*" or "mixed method*") OR AB (qualitative or interview* or "case stud*" or "mixed method*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (411,496) | View Details | Edit
S3	TI (experience or psych* or "quality of life") OR AB (experience or psych* or "quality of life")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (863,799) | View Details | Edit
S2	TI ("haematopoietic stem cell transplant" or "stem cell" or transplant* or "bone marrow" or HSCT) OR AB ("haematopoietic stem cell transplant" or "stem cell" or transplant* or "bone marrow" or HSCT)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (95,603) | View Details | Edit
S1	TI ("sickle cell" or "sickle cell disease" or "sickle cell anaemia" or "sickle cell anemia") OR AB ("sickle cell" or "sickle cell disease" or "sickle cell anaemia" or "sickle cell anemia")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (7,101) | View Details | Edit

PubMed (including MEDLINE), final number of studies = 535

Search	Actions	Details	Query	Results	Time
#10	•••	>	Search: ((((("sickle cell"[Title/Abstract] OR "sickle cell disease" [Title/Abstract] OR "sickle cell anaemia"[Title/Abstract] OR "sickle cell anemia"[Title/Abstract]) AND ("haematopoietic stem cell transplant"[Title/Abstract] OR "stem cell"[Title/Abstract] OR transplant*[Title/Abstract] OR "bone marrow"[Title/Abstract] OR HSCT[Title/Abstract])) AND (experience[Title/Abstract] OR psych* [Title/Abstract] OR "quality of life"[Title/Abstract])) AND (qualitative[Title/Abstract] OR interview*[Title/Abstract] OR "case stud*"[Title/Abstract] OR "mixed method*"[Title/Abstract])) OR (("Anemia, Sickle Cell"[Mesh]) AND ("Hematopoietic Stem Cell Transplantation"[Mesh])) Filters: from 1984/1/1 - 2024/12/31	535	12:02:29
#9	•••	>	Search: ((((("sickle cell"[Title/Abstract] OR "sickle cell disease" [Title/Abstract] OR "sickle cell anaemia"[Title/Abstract] OR "sickle cell anemia"[Title/Abstract]) AND ("haematopoietic stem cell transplant"[Title/Abstract] OR "stem cell"[Title/Abstract] OR transplant*[Title/Abstract] OR "bone marrow"[Title/Abstract] OR HSCT[Title/Abstract])) AND (experience[Title/Abstract] OR psych* [Title/Abstract] OR "quality of life"[Title/Abstract])) AND (qualitative[Title/Abstract] OR interview*[Title/Abstract] OR "case stud*"[Title/Abstract] OR "mixed method*"[Title/Abstract])) OR (("Anemia, Sickle Cell"[Mesh]) AND ("Hematopoietic Stem Cell Transplantation"[Mesh]))	535	11:59:15
#8	•••	>	Search: ("Anemia, Sickle Cell"[Mesh]) AND ("Hematopoietic Stem Cell Transplantation"[Mesh])	524	11:58:48
#7	•••	>	Search: "Hematopoietic Stem Cell Transplantation"[Mesh] Sort by: Most Recent	59,369	11:58:16
#6	•••	>	Search: "Anemia, Sickle Cell"[Mesh] Sort by: Most Recent	26,371	11:57:42
#5	•••	>	Search: ((("sickle cell"[Title/Abstract] OR "sickle cell disease" [Title/Abstract] OR "sickle cell anaemia"[Title/Abstract] OR "sickle cell anemia"[Title/Abstract]) AND ("haematopoietic stem cell transplant"[Title/Abstract] OR "stem cell"[Title/Abstract] OR transplant*[Title/Abstract] OR "bone marrow"[Title/Abstract] OR HSCT[Title/Abstract])) AND (experience[Title/Abstract] OR psych* [Title/Abstract] OR "quality of life"[Title/Abstract])) AND (qualitative[Title/Abstract] OR interview*[Title/Abstract] OR "case stud*"[Title/Abstract] OR "mixed method*"[Title/Abstract])	24	11:56:50
#4	•••	>	Search: qualitative[Title/Abstract] OR interview*[Title/Abstract] OR "case stud*"[Title/Abstract] OR "mixed method*"[Title/Abstract]	838,779	11:56:25
#3	•••	>	Search: experience[Title/Abstract] OR psych*[Title/Abstract] OR "quality of life"[Title/Abstract]	2,179,083	11:56:12
#2	•••	>	Search: "haematopoietic stem cell transplant"[Title/Abstract] OR "stem cell"[Title/Abstract] OR transplant*[Title/Abstract] OR "bone marrow"[Title/Abstract] OR HSCT[Title/Abstract]	877,433	11:55:43
#1	•••	>	Search: "sickle cell"[Title/Abstract] OR "sickle cell disease" [Title/Abstract] OR "sickle cell anaemia"[Title/Abstract] OR "sickle cell anemia"[Title/Abstract]	30,411	11:55:21

Appendix 3) Table of papers included in the Critical Literature Review

Authors, year, country	Purpose / Aims	Approach	Key findings
Abu al Hamayel et al (2021). USA.	To explore patients' experiences with pain and pain management during and after HSCT for SCD.	**Design:** Qualitative semi-structured interview study utilising thematic analysis. **Sample:** 10 patients, aged between 20-43 years old, who underwent HSCT for SCD at least one year previously.	Four key themes emerged: (1) **The pain trajectory:** patients described a fluctuating course of pain during HSCT, which often extended long afterwards and impacted all aspects of life, particularly affected by pre-HSCT experiences. Those who self-reported severe and frequent painful crisis prior to HSCT describing it as more manageable compared to those who had fewer painful crisis in the past. Pain tended to become less severe and often did resolve over time, though this ranged from a few months to two years, but when it did this enabled them to pursue activities such as re-enrolling in school, finding work, and exercising regularly, with positive effects on their physical and mental health. (2) **The role of opioids—a double-edged sword:** patients described opioids as reducing pain but insufficiently to balance significant adverse effects and burden. As pain improved, most attempted to stop or wean off them. recipients described opioids as having been beneficial in reducing pain but insufficiently to balance significant adverse effects and burden. As pain improved, most attempted to stop or wean off them, in myriad ways, with those who had support from healthcare providers having the most successful and positive experiences. (3) **Patient-centred decision making in pain management:** patients described insufficient agency in decisions about opioid use and weaning. (4) **Consequences of health-related stigma:** patients described experiences with stigma, mainly related to opioid use and weaning, as similar to pre-HSCT.
Bruce et al (2022). Canada.	To explore how quality of life (QoL) is affected from the perspective of adolescents who have undergone a nonmyeloablative matched sibling donor HSCT.	**Design:** Multiple case study methodology, including QoL inventories (PedsQL), interviews, intra-case analysis, pattern matching to allow for examination of patterns across cases, and cross case synthesis to review the results of each case. **Sample:** 5 participants 13–18 years (mean age of 15 years) one-year post transplant.	HRQOL improved for recipients after transplant in all HRQOL domains: • **Physical domain:** pre-transplant, 100% of patients experienced pain, and the majority suffered from fatigue, insomnia, and fevers often resulting in hospitalizations. Afterwards, participants reported improved physical wellbeing, with the capacity to take up sports and strenuous physical activities. • **Social domain:** pre-transplant, QoL was poor characterized by stigma, social isolation, and parental absenteeism. While in the 3-6 months after HSCT adolescents found the isolation period required to avoid infections difficult, over time they gained social acceptance from their extended families and communities who had previously stigmatized and excluded them, and were able to participate freely in activities with peers and their social life vastly improved. • **Psychological domain:** pre-transplant life experiences were overshadowed by psychological stress. The majority commented that their future was bleak and may lead to premature death. A year after HSCT, adolescents described a crisis free life with positive psychological outcomes. They felt relieved they'd truly overcome SCD and reported being satisfied with life, which they felt was as normal as everyone's.
Dovern et al. (2023). The Netherlands.	To explore the perspectives of adult SCD patients on the changes in their experienced health and	**Design:** Mixed methods approach, including a qualitative semi-structured interview, upon which a thematic analysis was carried out. Participants completed 9 questionnaires from the Patient Reported Outcome Measurement Information System (PROMIS)	Mean T scores on measures of HRQOL fell within normal limits after HSCT, though there was great diversity in the scores with three out of the ten scoring much lower due to the extensive organ damage they'd sustained prior to their transplant: • **Physical health:** Before HSCT, the negative impact of pain upon their lives was a theme for most recipients, and fatigue and the burden of treatment for SCD was also emphasised. First-year after HSCT, almost all recipients described

	personal life goals after being cured via a HSCT.	framework, and the researchers described the themes from the interviews in a narrative synthesis according to health domain (physical, mental and social health) and categorised in 4 chronological time phases (before HSCT, first-year after, current, and future expectations). **Sample:** 10 participants, with a range of 1-3½ years since transplant (60% female; age 19 - 49, median age 29.5 years).	the process as having been hard, due to the side effects (such as headaches, fever, hair-loss), but worth it. At the time of the interview, most considered living a pain-free life with more energy to do things as the biggest benefit, though some still experienced pain due to AVN and other damage caused by SCD, which was disappointing to them. In terms of future expectations, two recipients who had AVN hoped for further improvements through surgical interventions, while some females had worries about the effect of HSCT on their fertility. • **Mental health:** Before HSCT, recipients described feeling insecure, lonely, depressed, anxious and/or stressed due to SCD and its unpredictability. First-year after HSCT, while feelings of relief were reported by many, emotional struggles were common, with recipients expressing the need for psychological help and guidance, which was lacking. At the time of the interview, recipients described the mental processing of having HSCT as taking longer than physical recovery, and reported they were not cured of the mental impact of having SCD their whole life, again expressing the need for psychological support. In terms of future expectations, recipients reported optimism about the future, but a fear of SCD coming back. • **Social health:** Before HSCT, recipients felt they were lagging behind their peers due to frequent episodes of pain and hospitalizations, dependant on others, and missing out on life experiences. First year after, they felt isolated due to the hygiene restrictions, but described a big relief for their family and friends. At the time of the interview, recipients spoke of the new opportunities open to them and a more physically and socially active life, which at times felt overwhelming. In terms of future expectations, many recipients planned to return to study, find new jobs, and start families, though some reported financial worries.
Gallo et al. (2019a). USA.	To explore recipients' perception of HSCT success, personal life goals, and associated health-related quality of life (HRQOL) more than 1 year after HSCT.	**Design:** Mixed methods approach. Each participant completed a measure of HRQOL (SF-36) and short demographic questionnaire before participating in a semi-structured interview. Responses were entered into a computer-generated data matrix with pre-set themes of HSCT success and Personal life goals. The analyses comprised conventional content analysis, a series of data matrices and summaries, and descriptive statistics. **Sample:** 11 adults (19–52 years old), one year+ post-HSCT.	Themes from the content analysis: (1) **Theme 1, Success with Stipulations:** revealed that recipients had refined definitions about the level of success or failure for the HSCT, with some saying full success would come when they could stop taking anti-rejection medication. While some were pain free, others continued to experience chronic pain in relation to complications previously caused by SCD, such as avascular necrosis. Most recipients reframed the experience of HSCT to make it meaningful, whether or not it had been successful, with some drawing upon a strong faith-based system to help interpret their experiences. (2) **Theme 2, Shifting Expectations of Personal Life Goals:** is about the way that a HSCT affected recipients' expectations for their personal life goals. The three recipients with a successful HSCT had the highest HRQOL scores and described pursuing goals in relation to their careers, education and leisure activities that would have not been possible whilst having SCD. The four with avascular necrosis (AVN) had low physical role limitations scores, while the two recipients reporting a failed HSCT had reverted back to having SCD and most of their HRQOL scores were among the lowest and they continued to have SCD-related complications.
Gallo et al. (2019b). USA.	To provide descriptions and in-depth understanding of the recipient-donor allogeneic HSCT experience.	**Design:** Semi-structured interviews, utilising conventional content analysis. **Sample:** 7 recipients (mean age 36.3 years, range 23‑52 years old) and 6 donors, representing five recipient‑donor dyads and one recipient‑donor triad.	Five themes identified by the seven recipients: (1) **The downward spiral and a second chance:** the worsening of complications over time and increased episodes of pain due to SCD was emphasised as motivating factors, with HSCT being seen as a hopeful opportunity to live a longer, healthier life. (2) **Getting the monster off my back:** recipients spoke of the process of deciding to proceed with HSCT, including the influence and at times pressure to go ahead they experienced from family and health providers.

			(3) **Difficult and manageable:** many recipients spoke of being unprepared for the side effects they experienced, such as nausea and vomiting, with these being worse than expected. (4) **It was worth it:** recipients were satisfied with their decision to undergo HSCT, even the two whose transplants had failed. Most described the recovery period as being long, tedious and boring due to the need to restrict social activities, with some experiencing complications such as weight and hair loss which again they hadn't felt they'd been prepared for. Most of those with successful transplants spoke of their optimism for the future and for living a longer life where they were able to do things they hadn't previously been able to do. (5) **Relating to the healthcare team:** recipients' relationships with the transplant team or haematology clinic staff ranged from positive and trusting, to ambivalent and negative.
Hastings et al. (2019). USA.	To report the HRQOL scores of adults with SCD who had received haploidentical HSCT and relate these scores to their experiences with the transplant.	**Design:** Mixed methods, descriptive case-study approach, including qualitative semi-structured interviews and content analysis to see how this related to their scored on a HRQOL survey (SF-36v1). **Sample:** 5 adults (aged between 20-37) with SCD who received a HSCT.	Participants' with successful transplants and minimal complications scored highest in terms of HRQOL scores. The results of the study are presented in the form of five detailed case studies, with three main themes between them being described in the discussion section: (1) **The relief of being pain free:** Participants spoke of not worrying about future damage from SCD. (2) **New availability of opportunities:** recipients spoke of welcoming new goals and opportunities that were not previously available to them. (3) **No regrets about undergoing the transplant:** The four adults with SCD who had successfully undergone transplants unanimously agreed that it had been worth it, despite the complications, as did the one recipient whose transplant was not successful but who had chosen to have a second one. While knowing about the side effects wouldn't have led them to change their minds, some said it could have allowed them to mentally prepare for them.
Khemani et al. (2018). USA.	To determine patients' and caregivers' knowledge of HSCT, the factors influencing the decision to pursue HSCT, their experiences, and the impact of a successful HSCT on their daily living.	**Design:** Qualitative study-semi structured interviews utilising thematic analysis, and a focus group. **Sample:** 11 patient-caregiver dyads in the interviews, with the mean age of the recipient being 10.8 years old at the time of the HSCT. 12 in the focus group, with 9 being HSCT recipients.	Three prominent themes were revealed: (1) **Factors and concerns influencing HSCT decision making:** Participants reported the extent of the burden of SCD and progression of disease-related complications was the strongest factor in deciding to have a HSCT, as well as the availability of a sibling donor. (2) **HSCT experiences:** Transplant day was perceived as the beginning of a new life, or 'second birthday', but patients and caregivers had to deal with the arduous process of HSCT, such as having to be in hospital and away from family, and the side effects of the conditioning regime. The most common coping strategies described were distraction, prayer and maintaining a positive attitude. (3) **Impact of HSCT on daily life:** Participants spoke of discovering normalcy and a "new life" without the burden of SCD, and a sense of hope for the future. All participants were satisfied with their decision to have a HSCT and expressed no regrets.

Appendix 4) Quality appraisal results for studies incorporating qualitative methods to investigate the experience of HSCT for SCD.

	CASP question									
Paper	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?
Abu al Hamayel et al. (2021)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes
Bruce et al. (2022)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes
Dovern et al. (2023)	Yes	Yes	Yes	Can't tell	Yes	Yes	Somewhat	Can't tell	Yes	Yes
Gallo et al. (2019a)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes
Gallo et al. (2019b)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes
Hastings et al. (2019)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Can't tell	Somewhat
Khemani et al. (2018)	Yes	Yes	Yes	Can't tell	Yes	Yes	Somewhat	Somewhat	Yes	Yes

Appendix 5) Study advertisement

Research study into the experience of Stem Cell transplants for sickle cell disorder

What is the purpose of the research study?

We are interested in learning more about the experiences of people with sickle cell disorder who have had a stem cell transplant. We hope that this research will provide greater understanding of what this is like for those who have undergone this procedure and help in identifying what can be done to support people with this experience.

What does the study involve?

You will be asked to participate in an interview with Gary Bridges, which will take approximately 60 minutes. The interview will be conducted either in person or online using Microsoft Teams. You will be asked questions about your experiences of having a stem cell transplant and the ways in which your life has changed since.

Are you eligible?

You can take part in this research study if:

- You are aged 18 and above;
- You reside in the UK;
- You have a diagnosis of sickle cell disease and have had a stem cell transplant.

What Next?

If you are interested in taking part or if you would like more information, please contact:

Gary Bridges
Counselling Psychologist
London Metropolitan University
Email: gpb0023@my.londonmet.ac.uk

LONDON METROPOLITAN UNIVERSITY

Appendix 6) Participant information sheet

PARTICIPANT INFORMATION SHEET

To whom it may concern,

Thank you for your interest in this research study. I hope that the information provided in this sheet will help you in making your decision of whether to participate.

Brief description of research project

My name is Gary Bridges, and I am a counselling psychologist studying at London Metropolitan University who has worked with people with sickle cell disease for several years. As part of my Doctorate, I am carrying out research to discover more about people with sickle cell disease's experiences of having a stem cell transplant. Very little is known about this topic and only a relatively small number of transplants have been completed with adults in the UK. My hope is that by carrying out this research we will gain a better understanding of people's experiences of having a stem cell transplant so that we can learn what support they may require in undergoing the procedure and in adjusting to it.

What will taking part involve?

I would like to interview you for approximately one hour, asking you questions about your experience of having a stem cell transplant. The interview will be voice recorded and subsequently transcribed by myself. The transcription will then be read and explored using a qualitative methodology. Data from your interview will be used for my Doctoral level counselling psychology research project.

As a thank you for participating and completing the interview, I will give you an all4one voucher worth £20 which can be spent at a wide range of retailers (see https://www.one4all.com/new-where-to-spend for details).

How I will preserve you anonymity

All data will be held and processed in accordance with the Data Protection Act (1998). All recordings will be kept securely on a password protected digital voice recorder and deleted after they have been transcribed. When transcribing the interview, all identifying details (names, places, dates, etc.) will be excluded, and you will be assigned a random number. Paperwork related to data gathering such as the consent form, will be kept in a locked cabinet, before being scanned, shredded and saved separately from the interview transcript. All electronic files will be password protected and stored on a laptop, which itself is also password protected and only used by the researcher. Short, anonymised quotes from your interview may be used in material such as conference presentations, reports, or articles in academic journals resulting from the study, but these will not personally identify you. Data will be stored for a period of 5 years, after which it will be deleted or destroyed.

Your right to withdraw from the study

Participation is entirely voluntary. If you choose to participate you are free to withdraw by letting me know at any point up until the data analysis begins.

Are there any potential drawbacks to participating?
Aside from giving up some of your time, I do not anticipate there will be any drawbacks to you from participating in this study. Before starting the interview, I will ask you how you would like me to respond should you become distressed. You will be able to pause and take a break at any point during the interview. You are also not obliged to answer any question you do not want to. You will have the opportunity to discuss any feelings evoked at length post interview with me and be given information on sources of support you can contact in case you do experience emotional distress.

Potential benefits for you and others
My hope is that you will find the experience of talking about your stem cell transplant helpful in allowing you to reflect upon the changes it has made to your life and to your identity. I also hope the findings will help inform the type of psychological support provided to other people going through a stem cell transplant in the future.

If you would like to participate
If you would like to participate in this research study or have any further questions please do not hesitate to contact me by email: gpb0023@my.londonmet.ac.uk

We can then discuss the study further, and if you wish to proceed, agree on the practical details of conducting the interview. I will also send you a Consent Form outlining how I will use the material recorded, which I will ask you to sign and return to me.

If you have any complaints regarding any aspect of the way you have been treated during the course of the study please contact my research supervisor, Dr Samantha Banbury, via Email: s.banbury1@londonmet.ac.uk

I look forward to hopefully hearing from you soon.

Yours Sincerely,

Gary Bridges

Appendix 7)

CONSENT FORM

Title of research: An interpretative phenomenological analysis of the experience of receiving a curative Haematopoietic Stem Cell Transplant (HSCT) in adults with sickle cell disease living in the UK.

Contact person: Gary Bridges
Email: gpb0023@my.londonmet.ac.uk

Description of procedure: In this research study you will be asked a number of questions regarding your experience of having a stem cell transplant within a voice recorded interview.

	Please initial
I confirm that I have read the participant information sheet for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions, and have these answered satisfactorily.	
I understand I am free to withdraw at any time during the study without question up until the data analysis begins.	
I understand that the interview will be recorded using Microsoft Teams and a digital voice recorder.	
I understand that participation in this study is anonymous. My name will not be used in connection with the results in any way, a pseudonym will be used on the digital voice recording and all information that may otherwise identify me (e.g. names, address, places, dates, and friend's names) will be changed prior to transcription.	
There are limits to confidentiality however; confidentiality will be breached if any information is disclosed that indicates a risk to safety.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and password-protected and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I understand that this interview may evoke difficult and distressing feelings for me. I will be offered support and the opportunity to discuss these feelings at length post interview with the researcher. The researcher will also give information on further support available if required.	

I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.	
I agree to take part in the above study.	

Signature of participant: ……. Print name: ……. Date: …….	Signature of researcher: Print name: Date:

Appendix 8) **DEBRIEFING FORM**

Thank you for taking part in this research study. This research is part of a Doctoral project that I am conducting to discover more about people with sickle cell disorder's experiences of having a stem cell transplant. To reiterate, material from today's interview will be held securely and confidentially.

If you are interested in the results of the study, or if you have any questions about it, please contact me at the following email address: gpb0023@my.londonmet.ac.uk Emails will be checked regularly.

Please remember that if you wish to withdraw from this study, you may do so any time without question up until the data analysis begins. It may not be possible to do so at a later stage. Equally, if you have any questions or concerns you are more than welcome to address them now. If you have any complaints regarding any aspect of the way you have been treated during the course of the study please contact my research supervisor, Dr Samantha Banbury, via Email: s.banbury1@londonmet.ac.uk

If participation has raised any concerns or issues that you wish to discuss further, a number of agencies can provide advice and support:

If you or anyone else is in immediate danger:

- Call 999 or go to your local A&E department
- Call 111 - if you urgently need medical help or advice but it is not life-threatening, or contact your GP

If you need to talk to someone in confidence:

- Contact the Samaritans free-24 hour helpline on 116 123 or via email: jo@samaritans.org
  Website: www.samaritans.org
- Contact Shout Crisis Text Line – text 85258. Website: https://giveusashout.org
- You can contact the Listening Place for face to face support and online and telephone support: https://listeningplace.org.uk/
- Contact SANE by phone: 07984 967 708 or email: support@sane.org.uk. Website: www.sane.org.uk/support
- To access an NHS psychological therapies (IAPT) service local to you, follow this link: https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/
- You can also contact The Essenelle Foundation, a mental health charity supporting people with Sickle Cell and their families: https://www.theessenellefoundation.co.uk/

APPS & WEBSITES:

- Check out ways to help yourself cope during a crisis from the mental health charity Mind: https://www.mind.org.uk/need-urgent-help/what-can-i-do-to-help-myself-cope/

- Thrive: Mental Wellbeing is an evidence-based app to prevent and manage stress, anxiety, and related conditions: https://thrive.uk.com/
- Stay Alive (suicide prevention app): https://www.stayalive.app/
- DistrACT (app for information and advice about self-harm and suicidal thoughts): https://www.nhs.uk/apps-library/distract/
- Calm Harm (app to manage self-harm): https://www.nhs.uk/apps-library/calm-harm/

Appendix 9) **DISTRESS PROTOCOL**

Protocol to follow if participants become distressed during participation:

This protocol has been devised to deal with the possibility that some participants may become distressed during their involvement in the present research study on people with sickle cell disorder's experiences of having a stem cell transplant. This is a significant life event, and talking about this experience may evoke some intense memories and feelings for participants. This protocol is informed by published examples, such as those by Draucker et al. (2009) and Whitney & Evered (2022), and is very closely based upon that developed by Chris Cocking (2008) whilst he was working at London Metropolitan University and used in many subsequent research projects.

There follows below a two-step protocol detailing signs of distress that the researcher will look out for, as well as action to take at each stage. It is not expected that severe distress will occur, nor that the relevant action will become necessary, but the researcher, Gary Bridges, is a qualified counselling psychologist completing a doctorate at London Metropolitan University and has extensive experience in managing situations where distress occurs.

Mild distress:

Signs to look out for:

1) Tearfulness.
2) Participant's voice becomes choked with emotion/ has difficulty speaking.
3) Participant becomes withdrawn/distracted/restless.

Action to take:

1) The researcher will pause the interview and ask the participant if they are happy to continue.
2) The researcher will assess mental status, asking the following questions:
    a) "Tell me what thoughts you are having?"
    b) "Tell me what you are feeling right now?"
    c) "Do you feel you are able to go on with the interview?"
3) The researcher will offer them time to pause and compose themselves, and remind them they can stop the interview at any time they wish if they become too distressed.

Severe distress:

Signs to look out for:

1. Uncontrolled sobbing/crying, inability to talk coherently.
2. Panic attack- e.g. hyperventilation, shaking.
3. Intrusive thoughts or memories related to the transplant or other traumatic life event - e.g. flashbacks, re-experiencing.

Action to take:

1. The researcher will stop the interview and begin the debrief immediately.
2. The researcher will assess mental status, asking the following questions:
    a) "Tell me what thoughts you are having?"
    b) "Tell me what you are feeling right now?"
    c) "Do you feel you are able to go on with the interview?"
3. Grounding and relaxation techniques will be suggested by the researcher to regulate the participant's emotions and physiological state, and reduce agitation.
4. The researcher will reassure the participant that their experiences are normal reactions to significant events, accept and validate their distress, but remind them that this is not designed as a therapeutic interaction, and so will provide details of counselling/ therapeutic services available to them as detailed in the debriefing form.
5. The researcher will ask the participant if they feel able to go about their day, enquire into who is available to support them (e.g. friends, family), and generate ideas of how they can engage in self-care (e.g. activities that are enjoyable, pleasurable, soothing).

Appendix 10) London Metropolitan University Ethical Approval

Feedback from Ethics Review Panel

	Approved	***Feedback where further work required***
Section A	Yes	
Section B	Yes	Approved conditional on the applicant/supervisor establishing where ethical approval is required from the 2 charities for their project. This has been received and Chairs action taken.
Section C	Yes	
Date of approval		19 April 2023
NB: The Researcher should be notified of decision within <u>two</u> weeks of the submission of the application. A copy should be sent to the Research and Postgraduate Office.		
Signature of RERP chair		

Appendix 11) Interview schedule

Introduction: "Thank you for agreeing to take part in this study. I am interested in gathering details of people's experiences of having a stem cell transplant and their life afterwards as a way to help understand what it is like for them. I hope that this will help us discover what support people may need during and following this procedure. Do you have any questions before we begin?"

1. Can you tell me, what was your lived experience of having SCD like prior to having the transplant?

2. What mattered to you most when you decided to have the transplant?

   Prompts:

   - What were your hopes and wishes?

3. What are your most prominent memories of how the transplant was for you?

4. How did you cope with having the transplant and adjusting to life afterwards?

   Prompts:

   - *What strategies did you use?*
   - *Did you access psychological support / Do you think you would have benefited from psychological support?*

5. Since having your transplant, can you tell me about your lived experience of your body and how you relate to it?

   Prompts:

   - *Presence or absence of sensations such as pain, fatigue?*

6. Following your transplant, can you tell me how do you now think and feel about yourself?

   Prompt:

   - *Has this changed?*

7. Since your transplant, what have your experiences of relationships with other people been like?

   Prompts:

   - *Have they changed? Do people treat you differently?*
   - *With family?*
   - *With your sibling donor?*
   - *With friends?*

- *In your intimate relationships?*
- *Society at large?*

8. Since your transplant, can you tell me how you now view your future and any goals or plans you may have?

   Prompts:

   - *Having more confidence of being able to achieve things?*

9. Is there is anything else you would like say in relation to your transplant?

Ending: "Thank you for taking part in the interview. This part is over now and I have stopped recording, but before we finish, how has it been talking about your experiences today?"

Appendix 12) Section of Samuel's transcript with exploratory notes and experiential statements

EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
Emphasis on being strong in his convictions to have the transplant, despite considering his family's opinions	219 220 221 222 223	*Samuel:* But like I said, I was, I was...I'm strong enough in my kind of convictions that, you know, I was, I was going to do it anyway. I discussed it with my family...they, they gave me their opinion, erm, and, you know, they, they are supportive, but also, you know, are clear that it's not for them necessarily, but they, they were supportive, to be fair.	Emphasis on his own strength of convictions and independence *Differences in opinion from his family?* Conceding that despite members of his family not wanting HSCT themselves, they were supportive of his decision
	224 225 226 227 228 229	*Int:* Yes. And, I'm thinking actually, about the transplant itself. What would you say are your most prominent memories of the transplant? I suppose that may be the actual transplant process, the days leading up to it, the hospital admission, and I guess also the time afterwards. So that covers quite a big span of time, but for you, what sort of, are the most prominent memories of those different times?	
The period of time before and during the transplant as being completely separate from the time afterwards	230 231 232 233	*Samuel:* Yeah, erm, I think...obviously I don't know what the people that you've spoken to have, have had to say, but I would very much class the, the time before and during the transplant as one area and then the, the time afterwards is completely separate, I would argue.	Division of time into two completely separate phases. *Seems unsure how universal this time separation is? Aware I am interviewing other people.* "I would argue" – is he ready to defend this distinction?
	234	*Int:* Hmmm.	

EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
	235 236	*Samuel:* Erm, so I could answer this as two questions, essentially is what I'm saying that you're asking, I can answer in terms of the before and during.	Establishing how he intends to answer my question, which covers a large time period and different experiences
	237	*Int:* Hmmm.	
The transplant itself was quite smooth and straightforward **His familiarity with being in hospital made if manageable**	238 239 240 241 242 243 244	*Samuel:* I mean, I, I found the process pretty, I found the process during the process of the transplant, I found it quite smooth, I found it quite easy if I'm being 100% honest, and that's not, and that's not the case for afterwards but, but the process of, of the transplant itself… straightforward for me, I'm used to being in hospital, so you know, having to stay in a hospital for four or five, six weeks…it's boring, fine, but you know, it's actually fine, I could read a book, I can, I can occupy myself.	Transplant itself smooth, and quite easy. "Not the case afterwards" – pointing towards a very different/contrasting experience to come. "Straightforward" "I'm used to being in hospital". Familiarity with being in hospital. Boring, but can occupy himself. Self-efficacy – not perceived as being too threatening. Secondary appraisals of being able to cope.
	245	*Int:* Yes.	
The transplant day was low-key, underwhelming and nothing he couldn't handle	246 247 248 249 250	*Samuel:* Um, the transplant was, you know, quite low key, underwhelming kind of transplant itself, the transplant day. I mean, it was a little bit scary, but it wasn't, you know, like quite a big Hickman line gets put in, in that kind of thing, but nothing great, nothing that is completely, you know, nothing I couldn't handle, I could put it that way.	"Low key" "underwhelming" "a little bit scary" some anxiety disclosed, but described in mild terms. "Nothing I couldn't handle" – able to cope with it again emphasised.

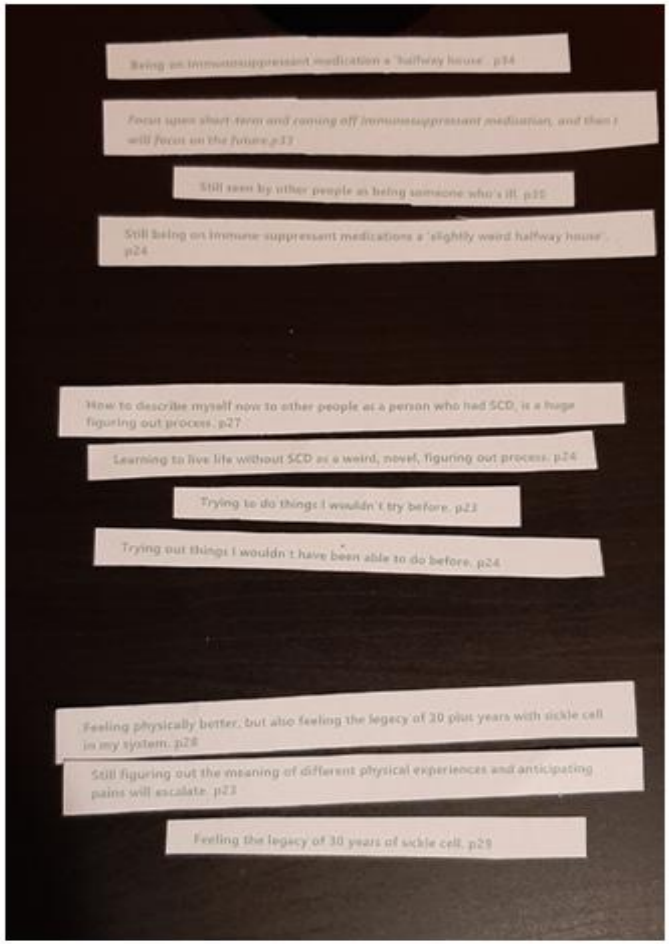
EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
	251	*Int:* Hmmm.	
He'd prepared himself for having chemotherapy	252	*Samuel:* And then the chemotherapy was, erm, it was like, it was, it certainly	Prepared myself for chemotherapy. Unpleasant, but manageable.
	253	wasn't nice, but I'd kind of prepared myself for, for the worst with that and,	
	254	yeah, I mean, you know, it's just, it's, to be honest with you I, I wouldn't…	Contrast the unusual situation of being well prior to HSCT with his usual experience of being in hospital when unwell.
Being in hospital for HSCT different from being in hospital when unwell with SCD	255	sickle cell's quite…, you obviously, if you have sickle, you go to hospital	
	256	when you're very unwell. Uhm, but obviously with a transplant like you kind	Is he saying it is therefore more manageable?
	257	of go when you're quite well and you're quite, you know, feeling in quite	
	258	good condition before you do it, so it was just a very, uhm…yeah, I found it	
The transplant process was low key and straightforward	259	all quite low key, to be honest with you, like the process was, was	"I felt good". Surprising statement.
	260	straightforward. I felt good.	
	261	*Int:* Mmm.	
Being mentally prepared for the transplant itself and the time in hospital	262	*Samuel:* Erm, maybe a few up and downs, you know, like I, I did get like a	"Few up and downs" – spoken in a way as to downplay the seriousness of it? Recall bias?
	263	big tooth infection, but nothing, nothing that I wasn't necessarily mentally	
	264	prepared for and nothing that really…erm, took me by surprise. I found, I	Emphasis on being mentally prepared and things being as expected.
	265	found the, the, the time that I was in hospital, I was, I, you know, had a long	
	266	time to prepare myself and I knew what to expect, and pretty much	
	267	everything that I expected to happen, happened. So, I was OK with that.	

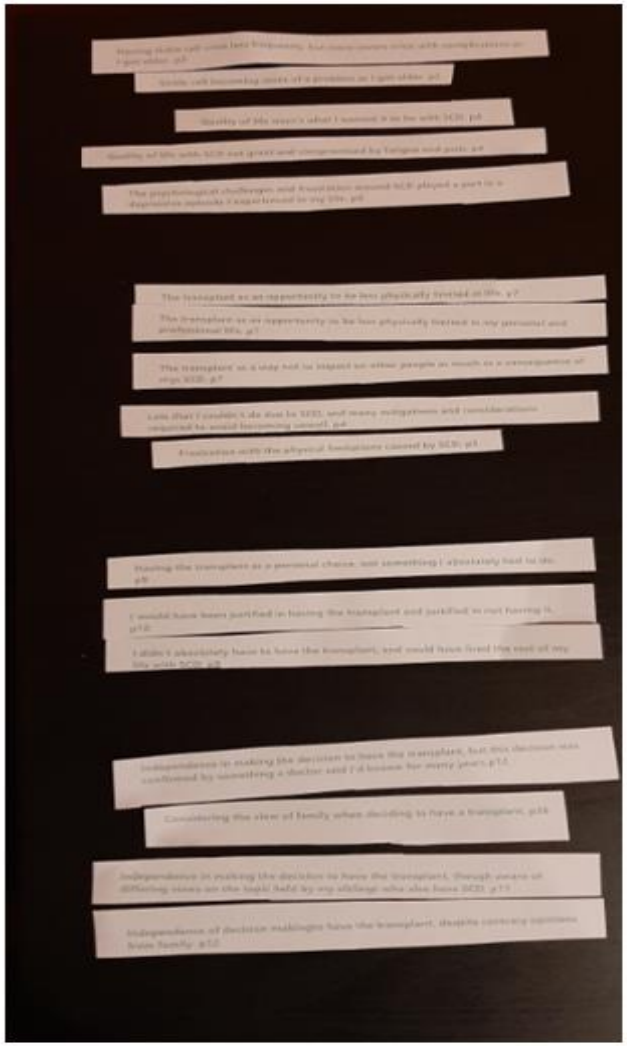
EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
	268 269 270	*Int:* Hmm. Hmm. But it sounds like it's sort of the period that you then say, the phase that followed after that, that you categorised that as maybe different?	
The time after the transplant was a lot more challenging	271 272 273 274	*Samuel:* Yeah. Yeah, yeah, yeah. So, I found that a lot more challenging. Uhm, I mean, I, you know……I knew that it was kind of like 3 months of, kind of, no contact, that's …frustrating, but that's OK. But then like, not going out in the outside world, you know, being very careful, but…	Time after the transplant and leaving hospital a lot more challenging. 3 months of no contact frustrating but OK. Sounds as if he was expecting and accepting of the isolation required after the transplant and felt able to do it.
	275	*Int:* Yeah.	
Taking immunosuppressant medication for longer than expected	276 277 278 279	*Samuel:* You know, you take immunosuppression for…err…a year, or it turns out actually longer, because I was, you know, I believe I was told it's kind of going to be a year, but I'm now being told it's more like 18 months. So, it's, it's a, it's a long process of…taking immunosuppression tablets, being very	Longer process of taking immunosuppressants than expected. 18 months rather than a year.
The need to be careful while taking immunosuppression medication	280 281 282	careful about going out, erm, you know, not picking up anything. Having to kind of second guess yourself, you know, inevitably picking up infections. I've had basically two serious bouts of infection this year…	Unfamiliar experience of having to be vigilant to avoid picking up infections "second guess yourself"? Compare to earlier statement about knowing how to live with SCD.
	283	*Int:* Hmmm.	

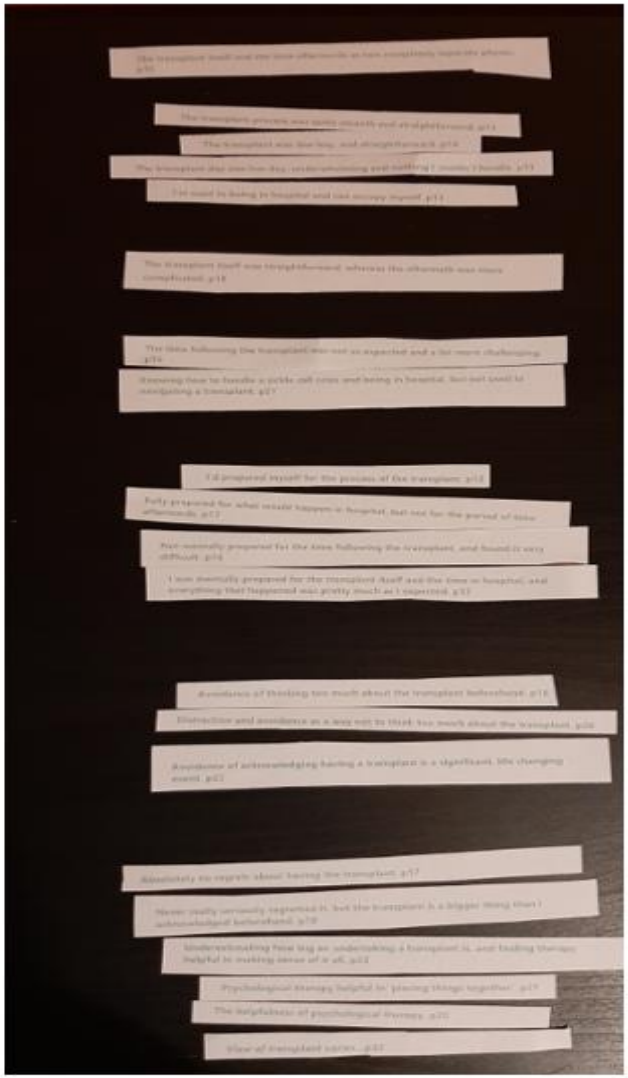
EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
Frustrating and scary experiences of being unwell after picking up infections	284 285 286 287 288	*Samuel:* Which have…one was kind of…frustrating, erm, and semi-serious, the other one was scary and semi-serious. And so, erm, that kind of how that was, I mean, I wasn't really prepared mentally for the level of…care that I have to take, the paranoid feelings about picking up infections. The, the stress of getting, you know, being unwell while taking immunosuppression.	Picking up infections – frustrating. Scary. "Wasn't mentally prepared". Paranoid feelings. Stress of being unwell. Did he not know or recall being told about this?
Not being mentally prepared for having to be vigilant and paranoid about picking up infections, and the stress of being unwell	289 290 291 292 293 294 295 296	*Int:* Hmmm, yes. *Samuel:* Yeah, I wasn't really…I don't mean, you know, maybe, maybe I didn't ask enough questions about that side of things, but like that's, that's what…I found that very difficult. *Int:* That sounds like, so that's, that's been the most sort of difficult and maybe unexpected aspects of the transplant, afterwards, the effects of the immunosuppressant, you've, you've been more susceptible to picking up infections, and having those too.	Taking some responsibility for not asking enough questions. Blaming himself? "I found that very difficult" Would he have found it less difficult if he'd ask more? Been more mentally prepared?
Being ready for what happened in hospital, but not for what happened months afterwards	297 298 299 300	*Samuel:* Yeah, yeah, yeah, yeah. Yeah, I mean, it might be that I've slightly…maybe rushed things a little bit, I don't know, but…Yeah, like I say, I, I was, I was fully kind of ready for, erm, the…what would happen in hospital, I just wasn't necessarily ready for what would happen kind of	"Maybe rushed things a little bit" – is he partially blaming himself for having picking up infections? Seems unsure. Prepared vs unprepared. Taking responsibility for this?

EXPERIENTIAL STATEMENTS		TRANSCRIPT	EXPLORATORY NOTES
Concluding his transplant was smoother than most people's	301 302 303 304 305 306	months down the line afterwards. Uhm, you know, I'm coming out the other side of it now and I'm sure in a year it'll be forgotten about, but at the time it's not, it's not great. I mean, absolutely…I absolutely have no regrets about having the transplant, and would do it again, but…but…I certainly…it can be…you know, the, the process of the transplant, from what I can gather, mine was probably smoother than most people's…	*The use of time projection to place things in a temporal perspective?* Will have forgotten about it. No regrets. Would do it again. How has he concluded this? Talking to other people who've had HSCT or healthcare staff telling him?
	307	*Int:* Hmmm	
The transplant itself was straightforward, whereas the aftermath was more complicated **The transplant is a bigger thing than he acknowledged beforehand, though not something he regrets doing**	308 309 310 311 312 313 314	*Samuel:* 'Cause mine, I won't say it was easy, I wouldn't say easy, but it was pretty straight forward, whereas the aftermath has been more complicated…I've never really seriously regretted it, but I've certainly had days where I've thought "why did I do this?" you know? So, it's a bit of a, kind of, journey, and as I say, I'll come out of it in a years' time and be very grateful, because I won't be in hospital, but you know, it's a, it's a…bigger thing than I had acknowledged beforehand.	Transplant not easy, but straight forward. Aftermath more complicated. Never seriously regretted it Days of questioning "why did I do this?" Use of forward time projection again to a better future again? Is this a way of coping? A bigger thing than he acknowledged
	315 316	*Int:* Hmmm. Yeah, yeah. And do you think with the information you had, you weren't prepared for that?	

Appendix 13) Initial search for connections across Samuel's experiential statements using the 'cut up' method.







Appendix 14) Table of PETS for Samuel

Table of Personal Experiential Themes from Samuel's Analysis		
Theme 1. Personal reasons for choosing to have the transplant		
Subthemes	**Experiential statements**	**Line numbers**
1. The negative impact of sickle cell getting worse	**Sickle cell becoming more of a problem as he got older**	**32-34**
	Having less frequent, but more severe sickle cell crises with complications as he got older	**35-49**
	His quality of life with SCD becoming increasingly compromised by fatigue and pain	**57-60**
	There were lots that he couldn't do due to SCD	**63-66**
	Many mitigations and considerations required to avoid becoming unwell	**66-70**
	Quality of life wasn't what he wanted it to be	**73**
	The frustrations of being physically limited by SCD	**83-93**
	Having an episode of depression related to SCD	**98-105**
2. Deciding to have the transplant as a personal choice he didn't absolutely need to have	**The transplant as an opportunity to be less physically limited in life**	**116-135**
	Being willing to take the risk	**139-141**
	The transplant was something he didn't absolutely have to do, and wasn't life or death	**156-161**
	A knife edge decision to proceed with the transplant, and there's a parallel universe where he doesn't have it	**168-170**
	Being justified in not having the transplant and being justified in having it	**177-178**
3. Independence in decision making, despite considering other's opinions	**His siblings who have SCD could not understand why he wanted the transplant**	**183-195**
	The influence of a consultant in confirming his decision	**209-211**
	Emphasis on being strong enough in his convictions to have the transplant, despite considering his family's opinions	**219-223**
	Imagining his parents would have been reluctant for him to have the transplant, but he'd still gone ahead with it	**645-651**
	Family being concerned about him due to it being a new treatment	**651-653**
Theme 2. Expected and unexpected experiences		
Subthemes	**Experiential statements**	**Line numbers**
1. The actual transplant and hospitalisation as straightforward and	**The transplant itself was quite smooth and straight forward**	**238-242**
	His familiarity with being in hospital made it manageable	**242-244**

something he could handle	**The transplant day was low-key, underwhelming and nothing he couldn't handle**	**246-250**
	The transplant process was low key and straightforward	**259-260**
	Concluding his transplant was probably smoother than most people's	**305-306**
	Being able to handle being in hospital due to his experiences with sickle cell crises	**363-365**
2. Challenges after leaving hospital	**The need to be careful while taking immunosuppression medication**	**279-281**
	Frustrating and scary experiences of being unwell after picking up infections	**282-285**
	The time after the transplant was a lot more challenging	**272**
	The transplant itself was straightforward, whereas the aftermath was more complicated	**308-310**
3. Being mentally prepared for the transplant, but not what followed	**He'd prepared himself for the worst in having chemotherapy**	**252-254**
	Being mentally prepared for the transplant itself and the time in hospital	**262-267**
	Taking immunosuppressant medication for longer than expected	**276-278**
	Not being mentally prepared for having to be vigilant and paranoid about picking up infections, and the stress of being unwell	**286-288**
	Being ready for what happened in hospital, but not for what happened months afterward	**299-301**
Theme 3. Underestimating what a big and life changing event the transplant was		
Subthemes	**Experiential statements**	**Line numbers**
1. Downplaying it's significant	**The transplant is a bigger thing than he'd acknowledged beforehand, though not something he regrets doing**	**310-314**
	He underplayed the significance of the transplant	**623-625**
	Underestimating what a life changing event the transplant was, and not like just going in and out of hospital with a sickle cell crisis	**380-388**
	In retrospect, concluding he didn't know enough about the HSCT process or ask enough questions	**477-479**
2. Avoidance of thinking too much about the transplant	**Consciously not overanalysing things in case he talked himself out of having the transplant**	**317-322**
	Acknowledging what a big deal both sickle cell and having a transplant are would make it difficult to go about his day-to-day life	**391-394**

	Working hard to avoid thinking about the transplant beforehand	**462-464**
	Coping by keeping things at arm's length	**498-500**
3. The role of psychotherapy in 'piecing things together'	**Starting therapy before having the transplant and finding it helpful to have continued with it**	**332-343**
	Therapy as helpful in piecing together the way the transplant was affecting other parts of his life	**358-362**
	Therapy as helpful in navigating the unfamiliar experience of having a transplant	**368-370**
	Therapy as helpful in making sense of it all	**389-390**
Theme 4. Figuring out how to live without SCD		
Subthemes	**Experiential statements**	**Line numbers**
1. Figuring out his new, embodied experience of being-in-the-world	**Trying out new things he couldn't do before**	**419-431**
	Knowing how to live his life with sickle cell but not knowing how to live it without it	**437-439**
	Still feeling pains within his body and anticipating he is going to have a sickle cell crisis, but which doesn't occur	**409-416**
	Feeling aches and pains that are the legacy of having lived a life with SCD in his body	**512-524**
2. Figuring out how to explain his new identity to other people	**It not yet making sense to him to tell other people he doesn't have SCD**	**480-484**
	It now being technically incorrect to introduce himself to others as having SCD	**486-488**
	Not yet having found the words to explain he no longer has SCD to other people	**489-495**
	Feeling unprepared of at the prospect of having to repeatedly explain he has had a transplant to other people	**537-545**
	Still seen by other people as being someone who's ill, which he thinks is true as he's still on immunosuppression medication	**549-550**
	Wondering if he'll always be seen by others as someone who has SCD	**551-554**
3. Being on immunosuppressant medication, a 'halfway house'	**Being focused on the shorter-term goal of coming off immunosuppressant medication before thinking further ahead**	**588-596**
	He'll think about the future after the big achievement of coming off the immunosuppressant tablets and getting that 'right'	**599-601** .
	Being at a 'halfway house' and needing to 'navigate this weird space' before being mentally ready to think what's next	**608-611**

Appendix 15) Prevalence Table

Smith et al. (2022, p.105) state that 'as a rule of thumb, to make a GET plausible, it must be inhabited by at least half the participants in the study'. While they do say this is not a hard and fast rule, I followed this advice, with the least populated subtheme being 'Changes in identity', a feature of the adjustment to life without SCD I thought of importance to Counselling Psychology and the provision of psychological therapy.

Group Experiential Themes	Subtheme	Prevalence: number of participants represented in sub-theme	Extracts provided in support of sub-theme
Leaving the Inferno	**The growing burden of sickle cell disease**	**6, Joshua, Amara, Ola, Samuel, Chima, Femi**	**5, Joshua, Amara, Ola, Samuel, Chima,**
	Considering the benefits and risks of the transplant	**6, Amara, Ola, Joshua, Samuel, Chima, Femi**	**5, Amara, Ola, Joshua, Samuel, Femi**
Travelling through Purgatorio	**Challenging experiences**	**6, Samuel, Femi, Ola, Joshua, Amara, Chima,**	**4, Samuel, Femi, Ola, Joshua,**
	Ways of coping	**5, Amara, Samuel, Chima, Joshua, Femi**	**3, Amara, Samuel, Chima,**
	Differing attitudes towards psychological therapy	**6, Chima, Joshua, Amara, Ola, Femi, Samuel**	**6, Chima, Joshua, Amara, Ola, Femi, Samuel**
Journeying towards Paradiso	**Getting reacquainting with the body**	**5, Chima, Samuel, Ola, Amara, Femi**	**4, Chima, Samuel, Ola, Amara,**
	Changes in identity	**3, Ola, Amara, Samuel**	**3, Ola, Amara, Samuel**
	Appraising the impact of the transplant	**6, Ola, Femi, Joshua, Samuel, Amara, Chima**	**5, Ola, Femi, Joshua, Samuel, Chima**