# A thematic analysis of encounters between those with sickle cell disease and their healthcare professionals where medication is discussed.

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## ABSTRACT

Sickle-cell disease (SCD) is a serious genetic blood disorder. At the time this study was conducted, only one drug treatment for SCD, hydroxycarbamide, was available. Research suggests that hydroxycarbamide is underutilised in the UK, and that adherence is low in those who take the medicine. The aim of the current study was to examine decision making and adherence from a relational perspective, specifically to answer the question: how do those with SCD who have been recommended to take hydroxycarbamide experience their medical encounters where the medicine has been initially recommended and where hydroxycarbamide is monitored over time?

Eight participants with SCD who had engaged in conversations with healthcare providers where hydroxycarbamide was recommended were recruited to take part in the current study. Semi-structured interviews were used to explore their experiences and data were analysed using reflexive thematic analysis with attachment theory as the theoretical framework.

Four themes containing nine subthemes were identified. The themes were: perceptions of vulnerability underpin the relationship; past relationships and templates impacting on the present; maintaining independence; and the adequacy of the response.

The results of this research suggest that relational dynamics between healthcare provider and patient are present and actively involved in the processes of initial decision making and subsequent adherence to hydroxycarbamide in those with SCD. Theoretical and clinical implications are discussed, along with some suggestions for future research. One important implication of the current study is that counselling psychologists working with those with SCD in healthcare settings will need to hold in mind multiple perspectives including evidence derived from the medical model, the patient’s own understanding of their illness as well as cultural and historical considerations. The clear contribution that counselling psychology can make to support healthcare practitioners to work relationally with those with SCD is also described.

**Key Words**: *sickle cell disease, shared decision-making, adherence, attachment theory, reflexive thematic analysis, counselling psychology.*

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## TABLE OF CONTENTS

# CHAPTER 1: LITERATURE REVIEW

## Overview

In this chapter, I will introduce the thesis along with my motivation for conducting the study presented within. I will also provide a review of relevant literature, a discussion of attachment theory, which provides the starting point for the theoretical understanding of the current study, an overview of the contribution of the study to counselling psychology and research aims.

*Given reflexivity is central to this research project, reflexive comments are included throughout this thesis in italic lettering. More explanation for this practice is provided in Chapter 2.*

## 1.2 Introduction

My interest in this area stems from my own professional experience; prior to training as a counselling psychologist, I worked as an academic conducting research in the field of health psychology, for the most part examining cognitive and behavioural theories predicting health behaviour change (primarily smoking, eating and physical activity) and designing and evaluating interventions targeting these behaviours. During this period, I also did some work examining medication adherence in people attempting to quit smoking and in those with chronic disease. I also spent some time working in a clinical health psychology department with children and young people with diabetes where facilitating medication and treatment adherence was the focus of much of the work. In this role I sat in on many consultations with doctors giving advice on available treatment choices. Following this, my first placement upon commencing training in counselling psychology was working in the haematology department of a large London hospital with people with sickle cell disease (SCD).

Cumulatively, these experiences prompted me to consider how I might work in these settings as a counselling psychologist with an academic background in health behaviour change, in particular to consider how the *being with* aspects of the interactions between healthcare professionals and patients seemed to be under-examined, both in the academic literature and in clinical practice, in favour of the *active ingredients* of these interventions. I felt that I could use my experience in both health psychology and counselling psychology to examine to the likely importance of experiential, relational aspects of medical encounters in determining the outcome of these encounters, and in the process contribute to the field of counselling psychology by evidencing the relevance of its core values to interventions delivered in healthcare settings.

Through my experience working in paediatric settings and my clinical training, I also became interested in how our early experiences, often framed in terms of attachment, influence how we experience and act in relation to others and thus in how relationships in childhood might also be implicated in the experience of medical encounters.

My contemporaneous work with people with SCD when devising this research led me to choose this group of participants to work with. Thus, data collection gathered information from eight participants using semi-structured interviews. Collected data were analysed using reflexive thematic analysis (RTA) A full explanation of the rationale for my choice of method will be provided in the corresponding sections.

### 1.3 Sickle-cell disease

SCD is a serious genetic blood disorder which has numerous negative physical and psychological impacts for those with the condition. SCD has been estimated to affect 1 in every 2000 live births in England and at the time this study was conducted, it was estimated that there were 12,500-15,000 people with SCD in England (National Institute for Health and Care Excellence, 2021c).

SCD is an inherited, single-gene disorder whereby one alteration in the gene coding for haemoglobin leads to the production of sickle haemoglobin (HbS) (Kavanagh et al., 2022). This gene confers protection against some forms of malaria and, correspondingly, was historically present in populations living in regions across sub-Saharan Africa; the Mediterranean, for example Greece and regions of Turkey; areas of the Arabian Peninsula and parts of India (Piel et al., 2014). In the UK, most people who are diagnosed with SCD are from Black backgrounds. Recent screening data found that of 245 babies screened positive for SCD at birth: 63.7% were recorded as Black African; 11.4% as Black Caribbean; 7.3% as being from other Black Backgrounds; 6.9% as East Asian (Including those from India, Pakistan and Bangladesh), 6.5% as being of mixed ethnic background with the remaining small proportion coming from a small number of children from, amongst others, white and other Asian backgrounds (NHS England, 2022).

SCD has an adverse effect on the movement of red blood cells through the body due to a change in the haemoglobin molecule. Red blood cells become deoxygenated, which causes them to distort into the eponymous sickle-like shape. The result of this is that these blood cells are less likely to pass freely through blood capillaries, and can form clusters that can block blood vessels (Dormandy et al., 2018; Kavanagh et al., 2022). These blockages, termed vaso-occlusive crises, (VOC), often referred to as “crises”, can result in a range of negative health impacts, most notably acute pain, but also acute chest syndrome (ACS).Those with SCD are also at increased risk of stroke, pulmonary hypertension, priapism, and leg ulcers (Kavanagh et al., 2022) in addition to an elevated risk of infection and progressive organ, tissue and neurocognitive degeneration (Centers for Disease Control and Prevention, 2017; Pecker & Darbari, 2019).

Avascular necrosis, which is a death of bone tissue due to lack of blood supply, can also occur due to the condition along with chronic arthritis, osteopenia and vertebral collapse meaning that those with SCD also often suffer from chronic pain. The impact of SCD on skeletal health can also lead to impaired growth (Almeida & Roberts, 2005; Giordano et al., 2021).

Due to these physical effects, it is perhaps unsurprising that SCD has a significant, negative impact on quality of life. Those with SCD experience a heightened prevalence of anxiety, depression and other psychological difficulties compared to general population estimates (Pecker & Darbari, 2019). The effects of the illness further impact on quality of life through detrimental impacts on educational attendance and opportunity, work and social life (Osunkwo et al., 2021). A systematic review found that those with SCD achieve less well academically compared to expectations, in part due to frequent hospital admissions, symptoms of pain, high levels of fatigue, but also cognitive deficits due to the illness (Heitzer et al., 2021). This constellation of early symptoms and impacts on education and attainment can have knock on effects across the lifespan; poor educational attainment can lead to reduced earning potential in adulthood, higher rates of unemployment and poverty, and potentially also early death (Haas et al., 2011; Harris et al., 2023).

### 1.4 Current treatments for sickle-cell disease

Unfortunately, treatment options for those with SCD are limited. One medicine that has been found to be effective as a treatment for SCD is hydroxycarbamide (termed hydroxyurea elsewhere in the world). Hydroxycarbamide is a disease-modifying drug, originally developed to treat cancer. A recent Cochrane Systematic Review of studies (Rankine-Mullings & Nevitt, 2022) reported that there is evidence to support the conclusion that hydroxycarbamide is effective in decreasing the frequency of acute complications, including pain episodes, in adults and children with SCD and in preventing life-threatening neurological impacts such as stroke. The authors concluded, however, that there was insufficient evidence on the longer-term benefits of the medicine.

There is also evidence that response to treatment with hydroxycarbamide can vary, with approximately 25% of those who take the medication not responding, or being considered poor metabolisers due to differences in genotype (Karamperis et al., 2021). Further, there is also evidence of side-effects and other negative consequences of hydroxycarbamide use. For example, although hydroxycarbamide is a chemotherapy drug, long-term use has also been linked to the development of cancer (Lewandowski et al., 2022). In addition to this, whilst evidence suggests that long term or serious adverse effects of hydroxycarbamide are rare (Steinberg et al., 2010), known side effects include impacts that are likely to be significant and unpleasant for those with SCD including, anaemia, rash, headache, nausea, discoloration of fingernails and effects on male fertility (Rankine-Mullings & Nevitt, 2022).

For over 20 years, hydroxycarbamide was the only available treatment for SCD in the UK. In October 2021, NICE recommended a new treatment, crizanlizumab, could also be made available to patients in the UK (National Institute for Health and Care Excellence, 2021a). The medicine was withdrawn, however, in January 2024 by the Medicines and Healthcare Products Regulatory Agency (MHRA) due to lack of evidence of effectiveness. Reports at this time claimed the drug was being used by relatively few people with SCD; only 200 patients at the point at which it was withdrawn (White, 2024), meaning that when this research was conducted, hydroxycarbamide was effectively the only drug treatment that would have been available to those with SCD, although those with SCD are also treated with blood transfusions, and stem cell or bone marrow transplants. These latter treatments are curative, but rarely undertaken due to potential high risk (NHS, 2022).

Whilst it is undoubtedly positive that any effective treatment exists, benefit is only possible if patients (a) decide to take the medication, and (b) if they do, take the correct dose, i.e. if patients adhere to their treatment regimen. As with any prescription medication, those with SCD cannot independently acquire hydroxycarbamide, relying instead on their doctor’s recommendation or agreement that they should take the medication in the first instance, and their support and monitoring of medication use over time. Relational experiences are thus crucial in determining the initial uptake and continuing adherence to hydroxycarbamide. More broadly, it could be argued that these experiences are the medium through which a compound enters the body and provides benefit, thus linking clinical research and real-world effectiveness.

### 1.5 The process of deciding to take a medicine.

Standards for Clinical Care of Adults with Sickle Cell Disease in the UK (Sickle Cell Society, 2018) recommend that hydroxycarbamide is discussed with all of those with

SCD who may benefit from its use. Three specific eligibility criteria are specified (p181/182):

- “Adults with SCD with three or more moderate to severe pain crises in a 12-month period;
- Adults with SCD who have a history of severe and/or recurrent (Acute Chest Syndrome, ACS, a severe lung-related complication of SCD)
- Adults with SCD and sickle associated pain or severe symptomatic anaemia that interferes with quality of life (QOL) or activities of daily living (ADL).”

It is further recommended that “Adults with SCA should be aware of the evidence of efficacy of HC [hydroxycarbamide] and be given information about the drug to enable joint decision making about its use” (p186). NICE guidance similarly recommends shared decision making as the basis for choices in healthcare (National Institute for Health and Care Excellence, 2011). Despite evidence of its potential benefit to those with SCD, and guidelines stating that it should be recommended to all eligible patients, data from the USA has shown that between 58-70% of those eligible for taking hydroxycarbamide were not taking the medicine (Elmariah et al., 2014; Lanzkron et al., 2006). It has been reported that hydroxycarbamide is also underutilised in the UK (Qureshi et al., 2018).

### 1.6 Adherence to medication

Adherence to (sometimes termed compliance with) a treatment regimen has typically been defined in the research literature as the extent to which patients take medicines as their doctor or other health care provider has prescribed (Osterberg & Blaschke, 2005). Within the context of chronic illness, those who fail to take their medicine as prescribed tend to have poorer health, leading to higher instances of anxiety, depression and poorer quality of life (Osterberg & Blaschke, 2005).

Unfortunately, adherence of those with SCD to hydroxycarbamide is frequently sub-optimal with reported rates of non-adherence, again in studies from the United States, of between 64 and 74% (Badawy, Thompson, Lai, et al., 2017; Badawy, Thompson, Penedo, et al., 2017; Candrilli et al., 2011). Poor adherence, it should be noted, is not an issue that is specific to those with SCD. A recent meta-analysis estimated that 42% of people with multi-morbidity are non-adherent with their prescribed medications (Foley et al., 2021). However, the issue of adequate adherence is particularly pertinent when it comes to treating SCD given the limited treatment options available (Haywood et al., 2014). Unfortunately poor adherence can have significant effects; lower rates of adherence to hydroxycarbamide in those with SCD have been associated with worse health outcomes, including more frequent SCD-related complications, low health-related quality of life, and increased health care utilization (Candrilli et al., 2011).

### 1.7 Counselling psychology applied to health care settings

As has been noted elsewhere (James & Bellamy, 2010), there is a potential tension here between the principles of the medical model which seeks to diagnose, treat, and ideally cure, and the six values of counselling psychology, below (Cooper, 2009, p120):

1. A prioritisation of the client’s subjective, and intersubjective, experiencing (versus a prioritisation of the therapist’s observations, or ‘objective’ measures).

2. A focus on facilitating growth and the actualisation of potential (versus a focus on treating pathology).
3. An orientation towards empowering clients (versus viewing empowerment as an adjunct to an absence of mental illness).
4. A commitment to a democratic, non-hierarchical client—therapist relationship (versus a stance of therapist-as-expert).
5. An appreciation of the client as a unique being (versus viewing the client as an instance of universal laws).
6. An understanding of the client as a socially- and relationally embedded being, including an awareness that the client may be experiencing discrimination and prejudice (versus a wholly intrapsychic focus).

Criticisms of the medical model from a counselling psychology standpoint have tended to focus on the validity of applying this model to psychological distress. Woolfe (2016, p11) has stated that "applied to mental health, the application of the medical model can be seen to have serious weaknesses". The converse relationship, in terms of the application of counselling psychology principles to medical settings, also highlights some issues. One issue of particular relevance for the current study is the tendency of the medical model to view individuals as *patients* with a collection of symptoms to be treated, for example with medicines such as hydroxycarbamide according to the criteria as set out in Section 1.5, above, as opposed to the holistic view of the individual espoused in counselling psychology, which encompasses, amongst other aspects, the individual's circumstances and personal perceptions of their condition (Blair, 2010). It could be argued that the medical model's positivism, which prioritises the evidence-base and promoting treatments for symptoms, is at odds with counselling psychology's pluralism, particularly with regards to prioritising and incorporating the patient's worldview alongside a commitment to evidence-based practice (Armitage, 2022; Blair, 2010).

This difference is of particular relevance to the current study. Given the demonstrated effectiveness of hydroxycarbamide in treating SCD for a large proportion of those with SCD, and the negative effects of non-adherence, a medical model view of the current situation regarding uptake of and adherence to hydroxycarbamide would be that higher levels of both should be encouraged and worked towards. However, as mentioned above, there are downsides associated with taking hydroxycarbamide for the person with SCD including unpleasant and visible side effects, and potential non-response to treatment. There is a strong possibility, therefore, that a patient's worldview, which could prioritise, amongst other variables, the avoidance of unpleasant side effects, might differ from the perspective of a healthcare provider, recommending a treatment based on research evidence.

*Coming from an academic background grounded in public health, my hope for this research ultimately was that it could contribute to increased levels of uptake of and adherence to hydroxycarbamide. However, I do not consider that this study is about encouraging those with SCD to take and adhere to hydroxycarbamide. As is explained throughout this thesis, this study is interested in the "being with" aspects of interventions, rather than in intervention content, or the aims of these interventions. In my mind, a study interested in encouraging uptake of and adherence to hydroxycarbamide would focus on these latter two aspects. I feel that it is not contradictory to assert that the study is simultaneously not concerned with encouraging increased uptake and adherence, whilst hoping that the results might* *be used to facilitate increased uptake and adherence. I do acknowledge, however, that there is some tension between this position and my position as a counselling psychology trainee. This will be discussed further in Section 1.10, below.*

## 1.8 Review of the literature

Relevant studies were sought using combinations of the keywords: “sickle cell disease”; (hydroxycarbamide or hydroxyurea); “shared decision making” and (adherence or compliance) in PsycINFO, Medline and Google Scholar. The reference lists of relevant studies were also searched, and studies that cited relevant studies were searched using Google Scholar.

### *1.8.1 Review of the literature on decision making*

Research conducted in the USA has identified several reasons preventing uptake of hydroxycarbamide including the perception of dangerous side effects, for example a fear of cancer, limited knowledge about hydroxycarbamide, and concerns about the effectiveness of the drug (Brandow & Panepinto, 2010; Brawley et al., 2008). As described in the section on hydroxycarbamide, above (Section 1.4) these concerns are not unfounded and reasons of those with SCD for not taking hydroxycarbamide should be taken seriously. However, as also described above in the same section, the evidence-base also supports significant benefits to taking hydroxycarbamide, especially within the context of SCD being a painful, life limiting illness with significant impact on quality of life.

As mentioned in the previous section, it is possible, therefore, that tensions may exist between a doctor’s perspective, drawn from the evidence-base which supports the use of hydroxycarbamide for symptom reduction for those specified in the eligibility criteria in Section 1.5, above, and the perspective of the person with SCD, for whom concerns about side effects and other adverse impacts, which are also supported by the evidence-base, may be to the fore. Previous qualitative research with young people with SCD in the UK (Renedo et al., 2020) described the extent to which those with SCD engage in *relentless self-disciplining* to maintain their health whilst staying on track to meet their other responsibilities and goals in life. This involves drawing on the expertise they develop about their own bodies and how best to manage their illness; thus, those with SCD will have a good understanding of what they feel is best for them based on their own experience, and this might not align with what the healthcare provider feels is best.

Shared decision making is the process used which aims to bring both the patient's and the healthcare professional's perspectives together to facilitate the making of informed decisions about treatment options. NICE guidelines (National Institute for Health and Care Excellence, 2021b, p32) define shared decision making as:

> "a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care… It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the options of choosing to have no treatment or not changing what they are currently doing always included)".

Research has found that significant numbers of patients prefer to be actively involved in decisions concerning their medical care (Kiesler & Auerbach, 2006). However, research has also found that, despite recommendations, shared decision making is not widely implemented in clinical practice (Couët et al., 2015).

There is also scant evidence on how shared decision making can be improved. No review of research evaluating interventions and strategies to increase shared decision making in those with SCD were identified. A Cochrane Systematic Review (Légaré et al., 2018) was identified that examined 87 studies aiming to promote shared decision-making by healthcare professionals in general. Use of shared decision making was evaluated either by objective observer-based outcome measures (OBOMs) or patient-reported outcome measures (PROMs). The review included studies that evaluated interventions targeting patients alone, healthcare professionals alone, or both. Interventions for patients included interventions such as decision aids and question prompt lists and interventions for healthcare professionals included educational materials and audit and feedback on communication skills. The authors concluded that although many different activities to increase shared decision making had been evaluated, the certainty of the evidence was weak and so it was not possible to conclude whether these interventions impacted upon shared decision making.

Where an evidence base seems to exist is in the use of patient decision aids, solely targeting the patients themselves, to facilitate decision making in health care settings. Despite recommendations for shared decision making, this also seems to be the approach to solving difficulties in decision making in healthcare settings. A recent Cochrane Systematic Review (Stacey et al., 2024) that included 209 studies found that Patient Decision Aids are effective at helping adults reach informed values-congruent choices as well as increasing levels of knowledge and, more accurate risk perceptions. Decisions are held to be due to variables within the non-deciding person. This review defines these interventions as (Stacey et al., 2024, p9): “designed to help patients make specific and deliberated choices among options (including the status quo), by, at a minimum, making the decision explicit, providing information on the options and outcomes (e.g. benefits/harms) relevant to a person’s health status, and implicit or explicit methods to clarify values. The patient decision aid also may have included: information on the disease/condition; costs associated with options; probabilities of outcomes tailored to personal health risk factors; an explicit values clarification exercise; information on others' experiences; personalized tailoring of information based on clinical characteristics; and guidance or coaching in the steps of making and communicating decisions with others”.

There is also little evidence on how to effectively promote shared decision making in those with sickle cell disease, and no research on the use or promotion of shared decision making in those with SCD in the UK was found. In a study from the USA, the Engage HU Study (Hildenbrand et al., 2022) compared two methods for optimising shared decision making for hydroxycarbamide in young children; a shared decision making toolkit created by the research team and usual care. Results showed that those in the toolkit condition had lower decisional conflict than those in usual care and reported that their clinician exhibited more shared decision-making behaviours than those in usual care. The intervention did not, however, impact on decision making.

A second study, also conducted in the USA (Smith et al., 2019) examined the impact of a change in informed consent procedure to improve the acceptability of hydroxycarbamide. Change was implemented at the clinic level from the original procedure which involved giving a non-SCD specific hydroxycarbamide information sheet to a verbal conversation from healthcare professionals that included an evidence-based presentation of risks and benefits of hydroxycarbamide, while addressing patient concerns regarding hair loss that had been identified as relevant for their target population. A retrospective examination of clinic data found that the conversation was associated with a statistically and clinically significant increase in use of hydroxycarbamide, an increase of 159%.

One further study (Krishnamurti et al., 2019), again conducted in the USA, designed a web-based patient decision aid that aimed to meet the decisional needs of those with SCD to help them to navigate different treatment options. The efficacy of this decision aid was then tested in “real life conditions”. The decision aid was targeted at the patient (or caregiver) and provided information to guide decision making presenting, for example testimonials from other patients regarding experiences with different treatments and information about the pros and cons of different treatment options, including hydroxycarbamide. The decision aid was compared with “usual care”, defined standard practice with their health care provider without the use of a patient decision aid. The study found no difference in favour of the decision aid in most outcomes, including reducing decision conflict and facilitating decision making.

Such research thus tends to focus on the exchange of information between doctor and patient, rather than the quality of communication or doctor-patient relationship. Thus, studies have tended to focus on *technical expertise,* and the content of interventions, for example the information that is provided to someone to extol the virtues of the medication, rather than the experience of *being with* as determining the decision to take hydroxycarbamide.

There is evidence that suggests that, despite patient preference for shared decision making and how it is emphasised in determining decision making, the doctor-patient relationship may play an equally important and independent role in the outcome of the decision-making process (Schoenthaler et al., 2018).

### *1.8.2 Review of the evidence on adherence*

Various studies, both quantitative and qualitative have found barriers to adherence to hydroxycarbamide in those with SCD such as people forgetting to take their medication, holding negative beliefs about taking the medicine, lacking sufficient confidence to self-manage their condition, having fear of side-effects and finding it difficulty accessing their medication (Alberts et al., 2020; Curtis et al., 2019; Fogarty et al., 2021).

Accordingly, interventions and strategies designed to facilitate improved adherence in people with SCD are directed at the non-adherent individual and are largely behaviourally oriented. A review of research evaluating interventions and strategies to increase adherence to hydroxycarbamide identified only six studies: two RCTs, three prospective studies and one retrospective chart review (Vick et al., 2021). Of the adherence strategies identified in the review only one, conducted by Green and colleagues (2017) involved significant support from health care practitioners (participants received home visits from community health care workers for social, educational, medical and adherence habit support). For the remainder, the focus was entirely cognitive or behavioural and the onus for increasing adherence was placed entirely on the individual with SCD or their family with extremely minimal or entirely absent contact with professionals. Three of the interventions were entirely non-interactive (Estepp et al., 2014; Olivieri & Vichinsky, 1998; Pernell et al., 2017) and the remaining two had minimal contact with health care providers: participants in the study conducted by Creary and colleagues (2014) received minimal feedback on their adherence and those in the study conducted by Inoue and colleagues (2016) received brief telephone call prompts only if their medication was not taken as scheduled. The author of this review found little evidence that these interventions had any impact on adherence, with some even leading to lower levels of adherence over time.

### *1.8.3 Decision-making and non-adherence as behavioural problems*

As can be seen from the above, both medical decision-making prior to taking hydroxycarbamide, and non-adherence to hydroxycarbamide, or indeed any medication have commonly been defined and examined as behavioural problems, with the determinants of each behaviour located largely within undecided or non-adherent individual. Logically following this, interventions, therefore, are based primarily on targeting these determinants in order to facilitate the “correct” decision and adequate adherence.

Such an approach is firmly in line with current practice in health psychology and behavioural science which dominate research and intervention development in these areas. For example, the Behaviour Change Wheel (Michie, Van Stralen, et al., 2011), which is the primary method used currently to design behaviour change interventions, uses *behaviour in context* as its focal point and uses this to determine the choice of intervention. Behaviour change is achieved by an interventionist applying a planned and coordinated series of activities that have been designed to alter patterns of behaviour. In this conceptualisation, interventions are something that are done *to* someone not *with*. Commonly referred to as *behaviour change* *interventions*, activities range from individual-level interventions to government policies such as changing or creating laws with the broad goal of improving public health by targeting the behaviour of individuals. These interventions generally target rational, intra-psychic variables within the individual such as beliefs, attitudes or intentions (Michie, Van Stralen & West, 2011).

### *1.8.4 Importance of the therapeutic relationship*

Such interventions, targeting behaviour as opposed to working with a whole person, often appear to ignore the importance of the relationship between patient and the person delivering the intervention contrasts sharply with the values of counselling psychology, as described above, particularly the importance of the individual subjective experience and the therapeutic relationship. Further, according to the person-centred principles espoused by Rogers (1967) that are often central to thinking in counselling psychology, change is not achieved by someone delivering an intervention *to* a client, rather, the aim is to form a relationship with the client, that they in turn can use for their own personal growth.

In mental health research, there is much evidence suggesting the benefits of a relational approach to working with clients. Several meta-analyses of interventions aiming to help those struggling with psychological problems have found evidence to support the benefits of forming a positive relationship between professional and client. A large meta-analysis, combining data from 198 studies (Barth et al., 2016) concluded that the effects of different psychotherapies were broadly similar when treating the symptoms of depression. The authors concluded that this was likely attributable to *common factors* such as the relationship between clients and their therapists. Other studies have also found evidence in support of the benefits of a positive relationship between therapist and client. Another large-scale meta-analysis conducted by Flückiger and colleagues (2018) that combined data from 295 studies found a significant, positive association (r=.28) between the therapeutic alliance and treatment outcome. The authors also found that this effect remained consistent across different characteristics of individual clients, countries and modes of treatment. A further meta-analysis also found a small to medium sized association (r=.28) between therapist empathy and the outcome of treatment (Elliott et al., 2018).

Recent developments in behaviour change research have moved even further away from acknowledging the importance of the therapeutic relationship, choosing instead to focus solely on the content of interventions, coding them for their ‘active ingredients, termed behaviour change techniques (BCTs) (Michie et al., 2013). Scant attention is directed towards *how* such components should be delivered or on the importance of the fostering a therapeutic relationship with a client. This is in spite of evidence showing that these aspects are important in determining the outcome of behaviour change interventions. Using the example of smoking cessation, despite evidence showing, for example, that the effectiveness of stop smoking interventions varies significantly across therapists (Brose et al., 2012) and that the application of greater counselling skills is associated with better smoking cessation outcomes (Hagimoto et al., 2018) *how* techniques are applied, nor the relationship between client and therapist is rarely examined (Hilton & Johnston, 2017).

### *1.8.5 Why the ways in which interventions are experienced might be important.*

As has been discussed above, research has demonstrated that the therapeutic relationship, and a client’s experience of therapeutic encounters play a central role in positive change in psychotherapy and that different outcomes in therapy may only be minimally attributed to specific techniques. The next section will consider different aspects of encounters between health care professionals and their patients that may also explain important variability in initial decision making and subsequent adherence to hydroxycarbamide.

#### 1.8.5.1 Attachment theory

As mentioned above, attachment theory was chosen as the theoretical framework for the current study. Attachment theory describes a psychobiological model of human development and relationships and was originally developed by John Bowlby and Mary Ainsworth (Bretherton, 1992). In brief, the theory posits that the quality of care received from our parents or other primary caregivers leads to differences in the ways in which we relate to others and can self-regulate our emotions in adulthood (Marrone, 2014). Attachment theory stands apart from more traditional drive-conflict models in psychoanalysis such as those espoused by Freud (e.g. Freud, 1955) and Klein (e.g. Klein, 1957) in that it proposes a developmental deficit model of understanding personality, grounded in the interaction of the external environment and internal processes in organising our internal worlds (Lemma, 2016). Attachment theory is a key theory in relational approaches to psychodynamic practice, thus aligning with the core values of counselling psychology (Rizq, 2010). The literature on attachment documents how the presence or absence of early attachment, and particularly attunement (i.e. how a caregiver attunes to the needs of a child) impacts upon emotional regulation that can last into adulthood (Porges, 2021; Van der Kolk, 1994). Importantly, and as is described below, patterns of attachment formed during childhood can subsequently manifest in interactions between doctor and patient in adulthood.

Four patterns of attachment have been identified, each implying variation in the structures that serve to regulate internal experience and guide both the development and the maintenance of object relationships (Lemma, 2016). *Secure* attachment develops under *ideal* circumstances whereby the child experiences primary caregivers who are available and sensitive to their needs. Growing up in this type of relationship allows the child to internalise a sense that others are dependable; this sense of security creates a *secure base* from which they can confidently learn about and explore their environment (Marrone, 2014).

The remaining three patterns of attachment are all forms of *insecure* attachment: those with *preoccupied* attachment may assume caregivers to be untrustworthy or unpredictable. As a result, those with this attachment style may heighten their emotional responses to increase the amount of attention they receive, thus maintaining contact. Those with an *avoidant* attachment style may act in the opposite manner, dampening down and not communicating distress or other feelings for fear of alienating caregivers. *Disorganised* attachment is the final category and is considered the most disturbed pattern; those with this attachment pattern frequently have had caregivers who frightened them, leading them to expect similar responses from those they interact with (Holmes & Elder, 2016).

Each attachment pattern is underpinned by what Bowlby described as an *internal working model*, cognitive, representational systems of self and others in interaction. For example, in insecure attachments, the responsiveness of the caregiver is not seen as reliable, thus the child must develop strategies to manage this perceived unresponsiveness (Lemma, 2016). When considering adult functioning, attachment theory has been described as an emotional regulation theory; the three categories of insecure attachment styles have been linked with an inability to effectively regulate emotion and the deployment of ineffective and sometimes counter-productive strategies. Thus, research has found that those with these attachment styles are vulnerable to symptoms associated with depression and other mental health diagnoses (Mikulincer et al., 2003). Those with anxious attachment have been hypothesised to use hyperactivation strategies such as demanding care and proximity from attachment figures, worry, rumination and hyper-vigilance towards attachment cues. In contrast, those with avoidant attachment styles often demonstrate a tendency towards self-reliance and use deactivating strategies, for example creating an emotional distance from others and the suppression of upsetting thoughts and memories (Malik et al., 2015).

Bowlby has hypothesised that the need for attachment is activated in adults when they are scared, distressed or ill (Bowlby, 1977). When feeling ill, stressed or vulnerable, people seek out a ‘secure base’ for comfort and safety (Holmes & Elder, 2016).The attachment system may be especially activated in response to physical pain. From the earliest age, pain leads to an expression of distress, in the hope that someone will either provide comfort or eliminate the source of the pain. Over time, the responses to pain become habitual and imbedded, and closely linked to the quality of experience with important caregivers  (Hunter & Maunder, 2015). Given the lifelong and painful nature of SCD, these processes would seem particularly relevant. Thus, consideration of how these patterns of attachment might play out in the health care setting when considering both initial decision making and adherence to medication in those with SCD is worthwhile.

### 1.8.5.2 Autonomy

Autonomy in healthcare is a critical issue that encompasses several important aspects. One influential definition of autonomy in healthcare defines autonomous decisions as those made with intention, with significant understanding, and without influence from controlling others (Beauchamp & Childress, 2009). As can be seen from the definition above, shared decision making operates in line with these principles; central to the process is the idea that patients should be provided with different options regarding their healthcare, and be allowed to voluntarily make choices, in the expectation that this process promotes patient autonomy (Ubel et al., 2018). Thus, in the current context, shared decision making is the process which is held to facilitate a discussion whereby a treatment like hydroxycarbamide is recommended to someone with SCD that allows them to autonomously weigh the option against their own understanding of SCD, concerns about effectiveness, and concern about the potential impact of side effects.

Whilst laudable that respect for autonomy is a value that guides clinical practice and decision making, the concept has also been critiqued as being connected to a Western, post-enlightenment concept that each adult is (p150) “a bounded individual who is able to live her life freely in accordance with her self-chosen plan, and ideally independently from controlling influences” (Dove et al., 2017). The potential limitations of such assumptions have led some to develop models of *relational autonomy* which expand understandings to acknowledge that when seeking to exercise personal autonomy, we are always located within broader social environments and interpersonal relationships. Such models de-emphasise independence and encourage us to ask how and why various forms of past and present social influences might undermine or support our ability to live our lives in our own way (Dove et al., 2017). Models of relational autonomy hold that individual capability and desire for autonomy is both situationally and socially shaped, and that social structures and cultural norms impact upon our lives, identities, desires, values and what we see as genuine possibilities (Mackenzie & Stoljar, 2000). For example, for psychological or cultural reasons, all clients may not know how to or want the responsibility of defining their own needs (Shillito-Clarke, 2010). This may be particularly relevant for the current study given the ethnic background of those with SCD in the UK. Whilst being aware that Africa is a culturally diverse continent, the culture in some African countries, e.g. Ghana, has been described as emphasising the wisdom of seniors and deference to doctors' and their judgement in decision making (Agyemang et al., 2021; Norman, 2015).

The provision of a secure attachment in the relationship between healthcare provider and patient may provide one means to facilitate the capacity of patients to make decisions in an autonomous manner that also takes into consideration their relational desire for autonomy. According to (Marrone, 2014) (p64) securely attached children "are very able to show distress (without falling apart) and make strong care-eliciting emotional communications. Securely attached children seem to be more resourceful, more flexible and display greater tolerance to frustration. They are more able to use the assistance of their mothers without becoming unduly dependent on it". Thus, theoretically, provision of a secure base might be expected to facilitate the ability to autonomously weigh the arguments for and against treatment in a manner consistent with their own beliefs and values, whilst also being able to balance their own need for support, which may be culturally derived, against potential dependence or coercion.

*Thus, although, as stated above, this thesis states that results could be used to facilitate greater uptake and adherence, this should not be considered as encouraging greater use, rather about facilitating conditions whereby the facilitation of the desired level of autonomy is maximised.*

#### 1.8.5.3 Self-regulation

One potential mechanism to link attachment experiences and the other behaviour of interest in the current research, medication adherence, is through self-regulatory capacity. Self-regulation refers to the process by which people manage their own responses or inner state (Baumeister et al., 2007). In the case of health behaviours such as adhering to medication, this often takes the form of resisting one response or behaviour which could provide immediate gratification or relief, for example stopping taking a medication that is perceived to be causing unpleasant side effects, in favour of a behaviour or response that is less motivating in the short term but linked with more abstract, distal goals, such as persisting in taking a medicine due to long term benefits that you have been told about. Accordingly, when someone resists stopping taking a medication to maintain the goal of long-term health, in spite of experiencing side effects, they have successfully self-regulated their own impulses (Baumeister et al., 2007). Increasing self-regulatory capacity, for example by encouraging people to set goals, monitor their behaviour and identify potential barriers are common features of behaviour change interventions (Michie, Hyder, et al., 2011; Michie et al., 2012).

Self-management behaviours, such as adherence, are typically achieved through behavioural and cognitive strategies that help people to structure their behaviour (Konig & Kleinmann, 2006). Theoretically, such co-ordinated actions can be regarded as an expression of one’s self as a representational agent, which is strongly linked with a developmental history of secure attachment (Fonagy, 2004). Research has identified associations between attachment style and different regulatory orientations. Adults who are securely attached engage in approach-oriented behaviours when responding to stressful situations, whereas those who are insecurely attached tend to rely more on avoidance-oriented behaviours (Park, 2010). Cumulatively, this research suggests that when people feel secure in themselves and in their relationships, they may be more likely successfully apply themselves to advantageous goals (Gable & Impett, 2012).

Conversely, adherence and other self-management behaviours have been shown to be more difficult for those with insecure attachment styles for a range of self-management behaviours including medication adherence (Hooper et al., 2016) attending dental appointments (Beaven et al., 2022) and adherence to COVID-19 guidance (Segal et al., 2021). These findings are particularly problematic when we consider that it is estimated that around 40% of us are insecurely attached (Holmes, 2014).

An important corollary of these findings is that it is incumbent on health care professionals to provide a relationship for patients that can be experienced as a ‘secure base’ in order to maximalise the effectiveness of adherence interventions. It is important to note that attachment orientations are not set in stone; new relationship experiences can lead to incremental changes (Arriaga & Kumashiro, 2019) meaning that the *how* medical professionals relate to their patients is likely important with regards to adherence, regardless of that patients early attachment experiences. Previous research supports the idea of an interaction between attachment style and doctor-patient relationship in medication adherence; a cross sectional quantitative study with 367 patients with Type 1 and 2 diabetes found that medication adherence in those with dismissive attachment style who also reported communication with their doctor was poor had significantly lower glucose monitoring and adherence to medication than all other categories of attachment (Ciechanowski et al., 2001).

#### 1.8.5.4 The importance of trust

Trust is another component of the attachment system that has been studied in regard to the experience and outcomes of medical encounters, albeit not necessarily with reference to that specific theoretical background. The development of anxious or avoidant attachment orientations are hypothesised to arise from interactions with parents or other primary caregivers that undermine individuals' confidence in the availability and responsiveness of attachment figures, which undermines the development of feelings of trust (Mikulincer & Shaver, 2003). The evidence base supports the notion that those with anxious and avoidant attachment styles are less likely to report trust in others (Fitzpatrick & Lafontaine, 2017; Mikulincer, 1998).

Trust is likely particularly important in regards to shared decision making, where a doctor is recommending a new medication, such as hydroxycarbamide, to a patient. Secure attachment experiences are also considered central to the formation of what has been termed *epistemic trust,* which is an individual's willingness to consider novel information from another as relevant to the self, generalisable and trustworthy (Fonagy & Allison, 2014). This process has been shown to be impaired in those with insecure attachment (Hayden et al., 2019).

In contrast to these intra-psychic definitions of the capacity for trust, located within the patient, definitions of trust in healthcare converge on the idea that that trust comes from a doctor’s interpersonal competence, and is associated with behaviours such as: demonstrating empathy and compassion, providing continuity of care, thoroughly evaluating problems, communicating clearly, being honest and respectful to the patient, providing appropriate and effective treatment, and understanding a patient's individual experience (Rolfe et al., 2014).

Trust has also been defined as a relational feeling induced within patients, however. According to Lupton (1996) trust in doctors means that the patient is able to share their intimate feelings, and allow their body to be touched and examined. A central feature of all definitions of trust in healthcare, is the patient’s belief that their doctor will put their interests first (Rolfe et al., 2014).

#### 1.8.5.5 The experience of discrimination in those with SCD

Beyond theory, there are other aspects of the quality of relationship between doctor and patient and the way that medical encounters with regards to hydroxycarbamide that may be particularly important in those with SCD, the majority of whom come from Caribbean or African family backgrounds (Centers for Disease Control and Prevention, 2017). In the UK, the recently published No One’s Listening Report (All Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021) found that those with sickle cell disease faced substandard care, negative attitudes and at times *blatant racism* when admitted into emergency departments or onto general wards. Data from the USA reports a similar picture: those with SCD are more likely to report poor interpersonal experiences of care when hospitalised compared to other patients. (Lattimer et al., 2010). Furthermore, a cross-sectional study of 273 patients with SCD found that 49% reported an experience of discrimination over the previous two years and that those reporting that they had experienced discrimination in their dealings with the healthcare system (Haywood et al., 2014).

Discrimination may also be of direct relevance to the uptake of hydroxycarbamide as one further barrier that has been identified in the literature is the level of mistrust towards the medical establishment in a group of patients that has historically has been discriminated against, stigmatised and marginalised (Hassell, 2008; Reeves et al., 2019). Those with SCD, due to the nature of their illness, can be frequent attenders of accident and emergency departments and the overwhelming majority of their attendance is related to pain. This presentation, in tandem with racist attitudes towards black and other ethnic minority patients, means that those with SCD are frequently stigmatised as drug seekers (Aisiku et al., 2009). This can be compounded by those with SCD frequently requiring higher doses of opioids due to habituation related to frequent treatment for crises (Boatright & Abbott, 2013). Research has shown that doctors often interpret tolerance as indicative of opioid abuse by those with SCD (Bergman & Diamond, 2013).

The recent “No one is listening report” (All Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021) described how those with SCD suffer due to these attitudes, with a person with SCD describing how (p36):

> “As sickle is mainly a black illness, they jump to the conclusion that we’re all ‘junkies’ and not in pain at all … If we were cancer patients it would be totally different, they have high doses of morphine, no questions asked and extra if they need it because they are mainly white people.”

There is evidence that experiences of discrimination negatively impact upon adherence. The above mentioned study by Haywood and colleagues also found that those who had experienced discrimination were 53% more likely to also report non-adherence to their recommended treatment. Trust in medical professionals appeared to mediate the discrimination/ nonadherence relationship, accounting for 50% of the excess prevalence of nonadherence among those experiencing discrimination. Although no data could be found examining experiences of discrimination and medication use in those with SCD, it does not seem beyond the realms of possibility that a similar impact would be present.

### 1.9 Contribution to counselling psychology

With regards to relevance to the field of counselling psychology, I am aware that traditionally, counselling psychology has focussed on helping those in distress and with psychological difficulties such as depression, anxiety and the effects of trauma. Accordingly, much of the discourse and academic work in the field is related to this work. However, there are opportunities for counselling psychologists to contribute to other areas of psychological practice, for example working in clinical health settings, and thus far there has been little academic work produced investigating the applicability of counselling psychology principles to this work. This research aims to address this gap. Given the links between physical health, mental health and behaviour, finding ways of working with people to enable them to make decisions about medications that are likely to improve their disease status, and subsequently adhere to their prescribed medicines is therefore a core skill for counselling psychologists working to support those working to improve their health.

Ethically, it makes sense for me to find the middle ground between counselling psychology and health psychology, to make the most of my advanced training in each. One key potential contribution for the current study for counselling psychology is to provide information for counselling psychologists working within health care settings, for their own practice, as supporting patients to make healthcare choices and maintain adherence is likely to be a core part of their role, but also as a means to demonstrate the importance and relevance of the core counselling psychology value of maintaining a relational focus when working with people. Counselling psychologists working within health settings will often work within multi-disciplinary teams, for example with doctors, nurses and other allied health professionals (Armitage, 2022). Having evidence to support the application of key counselling psychology values such as using the therapeutic relationship as a key facilitator of change is therefore also likely of value.

### 1.10 The current study and research aims

As has been described above, barriers to the uptake of and adherence to hydroxycarbamide in those with SCD, have been identified. However, to my knowledge, no prior study in the UK has examined the experiences of those with SCD when interacting with healthcare professionals with regards to the initial decision to take hydroxycarbamide, nor with regards to adherence over time. It is also not currently known to what extent relational aspects between doctor and patient impact on the choice to take or to continue taking hydroxycarbamide. This is in spite of the focus of disciplines such as counselling psychology that conceptualises the therapeutic relationship as a key driver of change as well as extant broader conceptualisations within healthcare that include aspects of the relationship between doctor and patient as contributing to adherence (Gearing et al., 2011; Osterberg & Blaschke, 2005)

*There is potentially some tension here where the current study could be viewed as ignoring known barriers to medication uptake and adherence in a marginalised group in favour of investigating participants experience and relational variables where there is less evidence of relevance. Whilst I acknowledge that this study is not primarily concerned with these known barriers, I would also argue that a surfeit of evidence supporting barriers to uptake and adherence and fewer papers in support of the importance of the relationship does not mean that the relationship is unimportant, rather, might be reflective of a positivist, medical-model ethos that prioritises intra-psychic variables and focus attention on the person with SCD as the problem when considering (arguably) sub-optimal levels of uptake of and adherence to hydroxycarbamide. As mentioned in Section 1.2, above, I feel that the being with aspects of interventions seem to be under-examined, both in the academic literature and in clinical practice, in favour of the active ingredients of these interventions. Thus, I am interested less in the barriers themselves, because these would be the focus of the content of an intervention, not because I do not feel that they are important. Thus, this research is conducted, not in the spirit of ignoring known barriers, but in the spirit of pluralism, and thinking about what else might be important.*

In terms of individual articles, one key study of interest is a qualitative study published by Jabour and colleagues (2019) that conducted semi-structured interviews with adults with sickle cell disease to examine their decision-making process with regards to taking hydroxycarbamide and the role of doctor-patient communication in this process. Data from the interviews was analysed with thematic analysis and a number of different themes were identified about the communication between doctor and patient and the decision to take hydroxycarbamide: accepting advice from the doctor to take the medication; deciding to take the medication based on a process of shared decision making; feeling pressured by their doctor; and feeling that they were not heard by their doctor.

The authors' epistemological position is not described in the study though it appears likely that they approached the research from a positivist stance. In the methods section the article reports that two authors coded transcripts for themes independently and had a proportion reviewed by a further coder which strongly suggests that they were working to achieve consensus between coders to arrive at an objective 'truth'. The authors also discuss the small sample size and likely lack of representativeness as limitations of the study, issues not typically of concern to 'big Q' qualitative researchers (Willig, 2013). The analysis and results also describe participants' experience of the doctor-patient relationship in a very limited, narrow way. Aspects of doctors' communication are described rather than broader, experiential descriptions of the therapeutic relationship which encompasses the feelings and attitudes that doctor and patient have towards each other and the way in which these are expressed (Noyce & Simpson, 2018).

To my knowledge, despite hydroxycarbamide being prescribed to those with SCD in the UK and both the recommendation of the medication, and regular monitoring and intervention to maintain sufficient adherence being recommended in clinical guidelines (Sickle Cell Society, 2018), little is known about how those with SCD experience such interventions. Accordingly, the aim of the current study was to examine decision making and adherence from a relational perspective, specifically to answer the question: How do those with SCD who have been recommended to take hydroxycarbamide experience their medical encounters where the medicine has been initially recommended and where hydroxycarbamide is monitored over time? This research was focused on generating information on participants' experiences and to generate hypotheses for further research.

Qualitative research is considered a suitable methodology for examining novel topics and so this study will utilise a qualitative, critical realist paradigm, with semi-structured interviews as the data collection method and reflexive thematic analysis as the analysis method.

### 1.11 Chapter summary

The aim of this chapter was to provide an introduction to the chosen project, a broad literature review of topics relevant to the project and an outline of the rationale for conducting the research. Finally, a research question was provided, defining the research paradigm that will be further described in the next chapter.

## CHAPTER 2: METHODOLOGY

### 2.1 Overview

The purpose of this chapter is to outline the methodological strategy chosen for this research, which was based on a qualitative enquiry. A pluralistic approach was chosen for the current study, with a critical realist stance that used semi-structured interviews as a data collection method and reflexive thematic analysis (RTA) as the method of data analysis with attachment theory as the theoretical framework. This chapter also includes the research paradigm, the researcher's philosophical perspective and reflexive positioning and the procedure and method of data collection and analysis.

### 2.2 Research Question

As stated in the previous chapter, the proposed project examines decision making and adherence from a relational perspective, specifically to answer the question: How do those with SCD who have been recommended to take hydroxycarbamide experience their medical encounters where the medicine has been initially recommended and where hydroxycarbamide is monitored over time?

*Originally, my plan for this research was to focus solely on adherence to hydroxycarbamide, and particularly on how the relationship between the person with SCD and their doctor was experienced in the initial difficult period of starting to take the drug, when side effects were new and likely aversive, and when the experience of a supportive relationship would likely make the most difference. I was mindful early on, however, that given the specificity of this scenario this could potentially be a difficult study to recruit for outside of a healthcare setting, and so decided to expand* *the research question to include the experiences of those who have had conversations with healthcare providers about hydroxycarbamide, regardless of whether they subsequently took the medication or not. Whilst I am aware that this likely has resulted in a less focussed study, as it now considers both initial decision making as well as subsequent adherence, I feel it still provides useful information, whilst also having the advantage of existing: given my subsequent difficulties in recruiting sufficient participants, as will be discussed below, I feel that ultimately this was the correct course of action.*

### 2.3 Counselling psychology and the application of research evidence

The current study is fundamentally concerned with practice, seeking to generate evidence that could be considered during an existing medical scenario. When applying research evidence to practice, counselling psychologists work within the scientist-practitioner mode and recognise the importance of evidence-based practice, which is a framework that holds research findings to be of fundamental importance to therapeutic practice. Within this framework research evidence is proposed as the best way to ensure that our clients receive the best interventions that psychology has to offer (Corrie, 2010). However, evidence-based practice has adopted a clear hierarchy of *best-available evidence* when determining what interventions work best for whom that excludes many types of research. These hierarchies  place systematic reviews and other sources of filtered information at the top of the pyramid. Unfiltered primary studies are further down the hierarchy, with randomised controlled trials deemed the highest form of this type of evidence, above cohort studies and other forms of quantitative research (National Health and Medical Research Council, 2009). Qualitative studies are not deemed to provide evidence that can answer the question of what intervention works best for whom. Thus, all *best-available evidence* is produced from a quantitative, positivist, empirical realist stance.

## 2.4 Conceptual and epistemological issues

Evidence-based practice, therefore, draws from a limited range of methodologies and associated epistemologies and ontologies compared to what is used in psychological research more broadly. Willig (2013) describes three main epistemological positions that are applied in the field: positivist; social constructionist and phenomenological. Empirical realism is the dominant position within mainstream psychology and is also the position inherent within evidence-based medicine. It holds that psychological or other attributes, for example knowledge, attitudes and beliefs, can be measured and once measured represent realities that can be characterised independently from the knower (Guyon, 2018). Someone conducting research from a realist position seeks to generate knowledge that represents something that exists in the ‘real world’ independent of the researcher (Willig, 2013).

Phenomenology is an approach to studying experience that has been espoused from a number of different philosophies which has as a central, unifying point a shared interest in trying to understand what the experience of being a person is actually like, particularly in terms of the things which are deemed to matter to us (Smith et al., 2009). In the phenomenological approach, researchers are also trying to generate knowledge that represents something that exists in the ‘real world’, but in contrast to empirical realist approaches, does not seek to explain or seek cause, rather to understand what it is like to have a certain experience and a participant’s perceptions, feelings and thoughts in the participants own words and terms (Willig, 2013).

In contrast to both of these approaches, social constructionism rejects the idea that such knowledge can be captured and described. Rather, the results of a research study are considered to be *constructed* by researcher and participants. Those who conduct research based on social constructionism therefore focus on *how* people talk about the world and their experiences and how they use language to construct their version of reality (Willig, 2013).

Whilst epistemology answers the question of *how* we can know, ontology answers '*what is there to know'* (Willig, 2013). Ontological concerns broadly range between realist, which maintains that psychological phenomena exist and can be measured, and relativist, which emphasises the broad diversity of interpretations that can be applied to the world, rejecting the presence of fixed variables that can be measured and have cause-effect relationships with each other (Willig, 2013). The social constructionist position is frequently described as relativist. An in-between ontological position is critical realism (Bhaskar, 1975) which suggests that psychological variables and phenomena exist and, therefore, can be measured. However it further holds that any knowledge generated, both by the participant and the researcher, is invariably constructed by language and experience and is therefore subjective (Willig, 2013).

Epistemologically, therefore, evidence-based practice is grounded firmly in empirical realism, and ontologically within realism. Conversely, inherent within counselling psychology research and practice is the embracing of a broad range of epistemological positions and research methodologies. This is due to counselling psychology having a commitment to *pluralism* as a central underpinning philosophy

(Woolfe, 2012). Philosophically, pluralism has been described as “the doctrine that any substantial question admits of a variety of plausible but mutually conflicting responses” (Rescher, 1993, p.79). Pluralism accepts that an absence of consensus in the formation of knowledge should be expected and considered as natural given all understanding flows from experience, and each of us lives different lives with experiences processed in fundamentally individual ways. With regards to research, a range of epistemological, ontological and methodological approaches are embraced and engaged with in an inquisitive, reflexive and critical manner that allows for tensions and contradictions (Jones Nielsen & Nicholas, 2016).

## 2.5 Chosen methodology and its underlying perspectives

### *2.5.1 Epistemological position and research paradigm*

In determining my own epistemological position, I feel it is important for me to reflect upon my background. As was mentioned in the previous chapter, before I commenced on the doctorate, I worked in academia conducting research in the area of health behaviour change, examining the validity of cognitive and behavioural theories purporting to predict behaviour change and designing and evaluating behaviour change interventions. All of this research was conducted from a positivist, empirical realist position. I feel that this position is valid for this research, which was coming from a public health angle where the aim is to design interventions that are effective and can be applied to populations, or to determine which interventions are most likely to be effective and communicate this information to practitioners.

However, there are also potential problems with this approach, not least that the framework of evidence-based practice is premised on an incremental approach whereby the interventions that become deemed *evidence-based* are those that are easier to research and lend themselves more readily to quantification and evaluation through randomised controlled trials. For example, cognitive behavioural therapy is the most researched psychotherapy (David & Cristea, 2018) and is the primary therapeutic modality delivered in NHS IAPT services, but has not conclusively been demonstrated to out-perform therapies where concepts are nebulous and less amenable to quantification (e.g. person-centred or humanistic) or whose proponents have traditionally been antipathetic to research (e.g. psychodynamic) (Shedler, 2010). As stated above, in practice, counselling psychologists work within the scientist-practitioner mode and recognise the importance of evidence-based practice, but draw from a range of approaches within psychology, which are supported by the evidence base to varying extents, such as cognitive-behavioural, psychodynamic, existential and humanistic (Woolfe, 2012).

My experience tells me that something similar has happened within health behaviour change research where outcomes such as medication adherence have become seen as an outcome entirely incumbent on the non-adherent person to achieve, determined in large part by intra-psychic variables such as the motivation, capability and opportunity to adhere. This is likely in part due to prominent voices within the field (e.g. Michie, Van Stralen & West, 2011) espousing targeting intra-psychic determinants of behaviour as the primary means to effect change. In following the prevailing research evidence, researchers appear to have taken an either/ or position, and forgotten that there are likely multiple variables that contribute to change (Castonguay & Beutler, 2006), and that some of these are not located within the patient.

My position is also informed by my experience in moving from being an academic to a clinician. Even ‘gold standard’ treatments have not been shown to work with 100% of the highly selected, limited samples of participants in clinical trials. For example, CBT plus medication for depression has been found in meta-analyses to benefit approximately two thirds of those receiving the treatment, leaving a sizable proportion not in remission following completion (Cox et al., 2014). Given this proportion of non-response, it seems unlikely that taking an either/ or position of fetishizing the evidence base is unlikely to serve the client sitting in front of me. I now consider myself epistemologically to be a pluralist and empirical realist as such approaches seek to achieve consensus. My contention now is that it is likely that both intra-psychic variables and the therapeutic relationship likely impact upon adherence along with a broad range of other variables. In wanting to examine decision-making and adherence from a relational perspective, I am also referring to the humanistic and person-centred roots of counselling psychology. This position holds that change cannot be facilitated by an interventionist delivering an intervention *to* another person, rather, that the role of the interventionist, in this case the doctor, is to foster the development of a relationship with the client that they can use for their own personal growth (Rogers, 1967).

Ontologically, in this project I will adopt a critical realist position (Bhaskar, 1975). This position holds that psychological phenomena do exist and can be recorded accurately. However, it contains the added corollary that any knowledge generated is inevitably subjective and constructed, both by the researcher and the participant, by all aspects of individuality, for example personal experience and language (Willig, 2013).

*It could be argued here that in consciously moving away from positivism that I cannot be considered truly pluralistic, given pluralism posits the acceptance and coexistence* *of multiple perspectives, and holds that there is not just one correct approach or truth. My understanding of positivism is that through empirical observation and scientific reasoning, an objective truth can be discovered. Thus, I feel that there is some contradiction between the perspective of accepting that one objective truth can be discovered, and that multiple truths can co-exist, but equally that there is some contradiction in embracing pluralism whilst tacitly rejecting positivism. I acknowledge this tension here. Consistent with my chosen ontology of critical realism, my understanding of pluralism is represented by valuing diverse ways of knowing and understanding, including those that may not align with positivist principles, such as interpretivism or constructivism. Thus, I see my approach as embracing and valuing a variety of perspectives, rather than as rejecting positivist approaches per se, but I am aware that there is a tension here that may not be entirely resolved by this position.*

### *2.5.2 Reflexivity*

As will be discussed in more detail below, Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022) was the chosen method for the current study. In RTA, reflexivity is outlined and incorporated throughout the research process. Braun & Clarke (2022, p13) in their guide to Reflexive Thematic Analysis emphasise the importance of delineating reflexivity, which they divide into three distinct aspects:

- Personal reflexivity, which relates to “how the researcher’s values shape their research, and the knowledge produced”
- Functional and disciplinary reflexivity, which relates to “how the methods and other aspects of design shape the research and knowledge produced”; and

- Disciplinary reflexivity, which relates to “how academic disciplines shape knowledge production”.

Kasket (2016) identifies some ways in which counselling psychologists can engage in reflective practice in research, including using a reflexive diary and this was the method used. As was stated above, reflexive comments detailing, for example, relevant details such as concerns, dilemmas and tensions are included throughout this thesis in italic lettering.

### *2.5.3 Alternative approaches considered.*

In my original research proposal, I had proposed phenomenology as the epistemology for this study and Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009) as the chosen methodology. IPA would have allowed me to conduct a detailed examination of the experiences of those with sickle cell in their own terms, for example of their experience of the relationship, or of adherence, but would not allow me to examine the causal process that I am interested in, i.e., whether those with sickle cell disease perceive that the therapeutic relationship impacts upon their adherence. I also rejected purely quantitative approaches as I felt that, in choosing which measures to use, for example which aspects of the relationship to measure, I would have been overly imposing myself on the research. I feel that a grounded theory approach, itself grounded in pluralism and critical realism allows me to strike a balance between these two positions.

I also actively considered using Grounded Theory methodology to analyse the data. Grounded theory is a method that allows researchers to move from data to theory, so that new contextualized theories can emerge (Willig, 2013). The methods of grounded theory uniquely integrate the typically separate processes of research and theoretical development ensuring theory is ‘grounded’ in the data, avoiding the imposition of pre-defined categories, and allowing new categories of meaning to develop. (Charmaz, 2006). However, although initially I was interested in trying to explain process and action in my research, over time I moved away from this position. Given theory generation stopped being an aim of this research, grounded theory was no longer deemed an appropriate approach.

*Initially, my research question was also to consider “What is the role of these experiences in subsequent decision making and adherence?”. However, over time, I felt that, perhaps due to my previous, quantitative research orientation, this question was perhaps fundamentally too positivist in nature. I feel that that to examine participants experiences of these conversations, to consider the psychological context within which such conversations occur and to consider participants’ responses to these conversations would be more illuminating, and perhaps more aligned with a big-Q qualitative research orientation which I am aiming for here.*

## 2.6 Data collection

### *2.6.1 Participants*

A total of eight participants took part in the research. Initially, 13 had agreed to take part, but of these, two ceased contact prior to an interview being set up, two started their interview, but these could not be completed due to technical difficulties, and the interview of one participant was aborted as it became clear early in the interview that they were not eligible.

*As I was interviewing this participant, I became suspicious based on their responses as to whether they were actually based in the U.K. or met the other eligibility criteria for the study and ultimately made the decision to terminate the interview. This was not an easy decision for me to make; given the time pressure of producing a thesis within a set amount of time and my awareness that recruitment was proceeding slowly, I was reluctant to deprive myself of a completed interview. In the time after I terminated this interview, I have also wondered whether my assumptions were correct and whether I might have excluded a genuine participant from taking part. As will be discussed further below, throughout the process of completing the thesis, there was at times tension between producing a "good enough" piece of work within a set amount of time and producing a piece of high quality research. On this occasion, I felt that my suspicions about this potential participant were sufficiently strong, and that ending the interview was the correct course of action to maintain the quality of the research. Following this, although being in the UK was clearly specified in the recruitment materials and information sheet as a criterion for eligibility, following this, I explicitly asked participants whether they were U.K. based before proceeding.*

Table 1, below, provides some basic information for each participant. Pseudonyms were used to protect participants' identity.

*Table 1: Participant details*

| **Pseudonym** | **Sex** | **Age** | **Ethnicity** | **When diagnosed with SCD?** | **Current treatments?** | **Length of time on hydroxy?** |
|---|---|---|---|---|---|---|
| Catherine | F | 28 | Black British | Aged 17 | Blood transfusions, Hydroxycarbamide | Eight years |
| Riley | F | 18 | Black British | “Childhood” | Hydroxycarbamide | Two years |
| Ivy | F | 22 | Black British | “Couple of months old” | Crizanlizumab | 14 years (but not currently) |
| Aidan | M | 29 | Black African | At birth | Pain medication, Vitamin D | Never |
| Vanessa | F | 27 | Black British | At birth | Hydroxycarbamide | Eight years |
| Elissa | F | 22 | Black African | At birth | Hydroxycarbamide, folic acid, amoxycillin, blood transfusions. | Six or seven years in current stint, plus more during childhood |
| Noah | N | 27 | Black British | Aged 25 | Hydroxycarbamide, pain medication, blood transfusions | Between three and four months |
| Eileen | F | 55 | African | At birth | Hydroxycarbamide | Almost one year |

### *2.6.2 Sampling and recruitment*

Participants were targeted who met the following criteria:

(a) Have been diagnosed with sickle cell disease;

(b) Have been recommended to take hydroxycarbamide by a medical professional;

(c) Reside in the UK (as this should ensure participants are likely to have similar experience of receiving treatment through the NHS).

*Originally when I was conceiving this study, I had in mind that I would aim to recruit only those who had been prescribed hydroxycarbamide and who had started taking the medication, thus sharing the experience of experiencing the titration process of starting to take the medication, experiencing any positive and negative effects, adhering or not adhering to their medication, all within the context of their relationship with the person or persons who recommended the medication to them. By restricting eligibility in this way, I would have had a group of participants who shared a similar experience. However, having experience of recruiting participants with chronic illness to take part in qualitative research in the past, I was mindful that the process could be difficult and time consuming and not necessarily compatible with the requirements of a time-constrained piece of doctoral research.*

*It might have been possible to achieve this had I recruited within the NHS. However, the administrative process for achieving NHS ethics would have taken a significant amount of time, with no guarantee of success. Further, it is possible that potential participants might have associated me with their hospital or medical team and thus felt less willing or able to be open and honest when discussing their relationship and experiences with these same people. Against this, it is also conceivably possible that the alternative might also true, that many participants would have good relationships with their medical team, experiencing them as a secure base, and I may have benefitted from this*

*Therefore, as I wanted to attract as many potential participants as possible, whilst remaining outside of the NHS, I decided to widen the scope of the study to investigate relational variables in the experiences of any one with sickle cell disease who had discussed hydroxycarbamide with their health care providers, regardless of whether they subsequently decided to take the medication, or continued to take it if it* *was commenced; as outlined in Chapter 1, the relationship between the person with sickle cell and their health care provider is conceived as the moderator which determines whether hydroxycarbamide is able to have a clinical effect. As hydroxycarbamide was the main treatment option for those in the UK at the time this study was conducted, this should allow the overwhelming majority of those with sickle cell disease to be eligible.*

Participants were recruited through the following channels:

(a) South Thames Sickle Cell & Thalassaemia Network. I attended a meeting of the network's support group on two occasions to present my project and invite participation.

(b) I asked my cohort at UEL to forward the study advertisement to those who they felt might be eligible.

(c) Snowballing: All those who took part in the study were asked at the end of the interview whether they knew of anyone who might be eligible to take part, and if so, to either pass study details on to them or to forward me their email addresses with consent.

(d) Social Media: I used social media platforms to identify and approach potential participants; for example I placed advertisements (see Appendix A) on forums for people with sickle cell disease on Facebook, having asked administrators for consent to advertise the research. I also placed advertisements on Instagram, Facebook and Twitter through the channels of the UEL Alumni Network. Students within UEL were also targeted, through advertisements placed on MS Teams.

Initially, only (a), (b) and (c) were used to recruit participants. However, no participants were initially forthcoming and so a revised ethics application was submitted that included strategy (c).

All participants were initially offered a voucher worth £20 for participation. In a previous research project I conducted which involved recruiting participants with chronic illness for qualitative research I found that recruiting participants with no incentive did not work and that this level of incentive was sufficient to generate interest. The level of incentive was subsequently raised to £40 in the revised ethics application when this initial incentive did not prompt sufficient participants to offer to take part in the study.

*The previous research I conducted had taken part several years prior to recruitment to the current study. On reflection, I feel that it is possible that the effects of inflation, and the cost of living crisis that started in the UK in 2021 meant that £20, which was sufficient to motivate interest in the first study, was no longer sufficient by the time I recruited for this study.*

The use of incentives to recruit participants into studies is not without controversy. Although research shows that incentives are effective; a meta-analysis found that incentives have greater effects when recruiting to studies where the response rate without an incentive is low (Singer et al., 1999), concerns have also been raised that incentives might coerce participants into taking part in research against their best interest (Millum & Garnett, 2019). It has been argued that the most important factor when considering the potential adverse effects of an incentive is whether the risks of a study have been minimised, and whether participants are fully informed about the nature of the study, including what is involved in taking part, how will any data be used, and how will data be stored (Singer & Bossarte, 2006). Based on my previous experience conducting similar research, along with the burden the study placed on potential participants, it was decided that the response rate to the current study would also likely be low, and that incentives would be needed to enable the study to be conducted. Sections 2.6.4 and 2.6.5, below, detail the ethical standards adhered to in the study to minimise the risk of harm to consenting participants.

*I found the recruitment process challenging, time-consuming and stressful. I attended my first meeting with the South Thames Sickle Cell & Thalassaemia Network online on February 9th; there seemed to be some interest within the group in participating and I remember logging off feeling optimistic. However, although I had made contact with a small number of potential participants through contacts on my course, it rapidly became clear to me that my initial recruitment strategy was inadequate. Following discussion with my supervisor and who helpfully suggested some potential avenues within the university, and some speculative emails to those within the UEL community, a revised ethics application was submitted on February 25th 2023, and approved on March 2nd 2023. Advertising through social media was then able to commence, and following this, there was a slow but steady drip feed of potential participants. I also raised the incentive for participation in this revised ethics application; I was concerned about potential coercion, through offering a relatively large sum, and was also concerned as to whether I could afford it. Against this, I felt that it was also possible that not recruiting through the NHS might mean that participants would not feel that deciding not to take part might jeopardise their* *healthcare or relationships and thus might feel more open to opt in only if they were genuinely motivated to take part.*

*Ultimately, my fear of not completing the thesis proved greatest and I felt that a "kitchen sink" approach of broadening recruitment to social media, whilst also increasing the incentive, would likely give me the best opportunity to collect the data I needed. It is possible that this represents a further tension; that of being simultaneously an ethical academic researcher, aiming to answer a research question in as valid a manner as possible, upholding the rights and wellbeing of their participants, whilst also being a doctoral student for whom the stakes of completion versus non-completion are extremely high. As mentioned above, I feel that this tension is present in many of the decisions I have made in this thesis, between wanting to produce the best work possible, whilst also, feeling pressured, for personal, professional and financial reasons, to produce a piece of work that gets me across the line, and allows me to move forward in my career.*

### *2.6.3 Semi-structured interviews*

RTA is a highly flexible method that can be done with datasets generated from a broad range of data collection methods. For the current study, data collection consisted of semi-structured interviews. These interviews provide an opportunity for the participant to talk freely about an aspect of their life or experience within the bounds of the research question set by the researcher (Willig, 2013). An interview schedule was used with open-ended questions and prompts. Separate questions were devised depending on whether participants had decided to take hydroxycarbamide or not, or who were adherent or not (see Appendix B). Examples of questions include:

- *What has your experience of taking hydroxycarbamide been?*
- *What can you tell me about your experience of being recommended to take hydroxycarbamide?*
- *What was your experience of taking the decision to take hydroxycarbamide?*
- *Do your healthcare providers check adherence?*

Each interview opened with a set of straightforward demographic questions, their diagnosis of SCD and current medication, to allow participants time to settle into the interview and for rapport to develop before proceeding with more personal questions (Willig, 2013)

As is appropriate for the current study examining relational variables in medical decision making and adherence, it is also important to pay attention to the contextual features of interview material. Potter and Hepburn (2005) have discussed how researchers often take data garnered from interviews at face value, ignoring the status of the interview as a conversation between two people, each having different stakes in the interview and coming to the conversation from a different angle. It has also been argued that it is important for researchers to consider the possible impact of their own social identities (e.g. age, gender, nationality, ethnicity, social class etc…) on the interviewee (Willig, 2013).

*The concept of being an insider researcher, if I am a member of the group I am studying, or an outsider researcher, if I am not a member of the group I am researching (Braun & Clarke, 2022) is clearly relevant to the current project. As mentioned in the previous chapter, SCD primarily affects those coming from Caribbean or African family backgrounds. In my study, all participants either* *identified as Black British, Black African, or African, whereas I am white and Irish. Perhaps in the past, this would have led to me being considered marginalised in the UK, but this was not the case in 2023 when these interviews were conducted. I therefore was conscious that I was conducting this research coming from a more privileged position than my likely participants, who, it had been recently reported, often faced "blatant racism" within the healthcare system (All Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021).*

*Given this disparity in privilege, I was concerned at times whether my conducting this study was exploitative; a privileged person gathering data from a marginalised group solely to gain a qualification to benefit himself. However, as mentioned in the previous chapter, part of the inspiration for this study was borne out of my experience of working with people with SCD, and the intersection of this work with my previous academic experience. I had a sense that there was genuine question to be addressed, with potential benefit for those with SCD and that, given my qualifications and previous academic experience, I was in a position to produce this research. There is no straightforward solution to this tension; As stated in Braun & Clarke (2022) (p217) "Simply avoiding research that might involve representing the other is not the simple solution". I will attempt in the current research to sit with this tension and produce what I hope will be a worthwhile piece of research, whilst also examining the role of my privilege in any of my assumptions, interpretations and conclusions.*

Interviews were conducted remotely using MS Teams. Allowing interviews to be conducted remotely, in a place and at a time convenient to participants was felt to remove a significant barrier to participation, potentially increasing the potential population who might be eligible. I also felt that this would be ethically more appropriate for this population; those with SCD are classed as extremely clinically vulnerable and many have been shielding during the recent pandemic. It would not have been appropriate or safe, therefore, to ask potential participants to travel to a separate site to complete interviews, nor for me to interview them in their homes.

### *2.6.4 Ethics*

Ethical approval was granted from the University of East London's ethics committee on October 28th 2022, subject to minor amendments.  As mentioned in above, an amendment form was subsequently submitted to the UEL ethics committee, and approval granted on March 2nd, 2023. Finally, a change of title for the research was approved on July 15th, 2024 (approval letters are in Appendix C).

This study adhered at all times to the British Psychological Society's Code of Human Research Ethics (Oates et al., 2021). The Code prioritises respect for the rights and dignity of participants in researcher and is based on four main principles: respect for the autonomy, privacy and dignity of individuals, groups and communities; scientific integrity; social responsibility; and maximising benefit and minimising harm. Ultimately, these guidelines emphasise the responsibility of considering participants' wellbeing, whilst also respecting scientific integrity. A risk assessment was developed to achieve this. The primary potential risk identified was that participants may experience discomfort or distress when disclosing information about what is a life-threatening illness that carries stigma (Bulgin et al., 2018). To address this risk, I planned to 'check in' with the client to verify whether they were able to continue with the interview. Further advice and details of help were also offered to all participants in a debrief sheet (see Appendix D), emailed following completion of the interview.

### *2.6.5 Procedure*

Prior to participation, participants received an information sheet (see Appendix E) providing the study title and a description of study aims and procedures. A consent form (see Appendix F) was also sent to participants prior to their participation, and all participants were asked whether they had read the information sheet, whether they had any questions, and to provide verbal consent at the start of each interview to ensure that they were happy to continue. The consent form outlined that participation in the research was voluntary, that participants understood how data would be collected and stored and what would happen once the study was completed. Participants were also reminded that they had the right to withdraw their data, so long as this was done within three weeks of their interview.

Interviews lasted between 26 and 69 minutes. Following the end of the interview, each participant was sent an email thanking them for their participation with the debrief sheet as an attachment (see Appendix F). Participants were also sent their voucher for participation at this point through the all4one website.

## 2.7 Analytic Approach

### *2.7.1 Reflexive thematic analysis*

Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022) was chosen to analyse the data. RTA provides a flexible method that is compatible with the theoretical, epistemological and ontological orientation of the current study. Central to this iteration of TA is the central role attributed to researcher subjectivity in the interpretation of data, use of theory and the skills and resources available to them (Braun & Clarke, 2022).

The main aim of RTA is to construct rich themes and identify recurring patterns of shared meaning across a dataset (Braun & Clarke, 2022). The current research utilises a dual inductive-deductive approach to RTA; coding and theme development were driven both by data content and through reference to attachment theory as the theoretical framework for the current study, alongside other existing relational, theoretical constructs as outlined in the previous chapter.

Thus, RTA, as utilised in the current study, acknowledges and incorporates my preconceived personal motivations, theoretical orientation and academic skills and knowledge, providing an important cornerstone for the analytical process (Terry et al., 2017).

*As discussed above, this research was conducted from a pluralistic position that sought to simultaneously consider diverse perspectives, for example relational approaches when working with clients compared with interventionist or medical model approaches and my identities both as a researcher in health behaviour change and as a counselling psychology trainee. I felt that the flexibility inherent in the method would provide me with a means to incorporate these varied perspectives and interpretations, whilst also encouraging me to be aware of my own biases and assumptions.*

### *2.7.2 Recording of the Data and Transcription*

Each interview was audio-recorded using MS Teams, which also produced a rudimentary transcript. These transcripts were subsequently corrected, and each transcription aimed to produce a verbatim account of each interview. Transcribing conventions were adapted from Braun & Clarke (2022). In line with the data management strategy, anonymisation and pseudonymisation was performed during this process to maintain participants' confidentiality.

### *2.7.3 Data Analysis*

Data were subsequently analysed according to the steps and sequence described in Braun & Clarke (2022): Familiarising yourself with the dataset; Coding; Generating initial themes; Developing and reviewing themes; Refining, defining, and naming themes; and Writing up.

#### 2.7.3.1 Phase 1: Familiarising yourself with the dataset.

According to Braun & Clarke (2022), familiarisation involves three separate practices: to develop a deep and intimate knowledge of the dataset; to critically engage with the information as data; and to create notes of thoughts related to the dataset. Each interview was listened to once, and each transcript read through twice with the aim of immersing myself in the data. The notes produced at the end of this process can be seen in Appendix G.

#### 2.7.3.2 Phase 2: Coding

The aim of a code is to capture a specific and particular meaning within the dataset that holds relevance for the research question (Braun & Clarke, 2022). At this point, coding was used to identify explicit content in an initial attempt to identify recurring patterns. Codes were initially written in the margin of printed transcripts (see Appendix H for an example of a transcript showing this initial coding process). Each transcript was coded twice. As recommended by Braun & Clarke  (2022), transcripts were coded in a different order each time in order to minimise the influence of order on generated codes. Following the second round of coding, generated codes were added to an Excel spreadsheet, at which point code label names were compared, and consolidated if appropriate.

*I found coding to be a very difficult process; I found it difficult initially to discern which of the data held relevance for the research question. Although I had resolved to code at the semantic level, I could not help but pay attention to potential latent meanings within the data. Further, although I understand the pragmatism inherent in research that involve making decisions on what to focus on or not, and that this is central to the RTA process, I felt it unethical somehow to ignore some of what my participants told me. Perhaps this was in part due to my burgeoning role as a psychologist who supports clients over my previous identity as one who conducts research. I also felt like I wanted to represent what my participants had told me. After my first round of coding, I had generated 158 codes. I took some time away from coding at this point in the hope that I could gain some emotional distance from the task and reorient myself to the task at hand, which was to have a wieldy set of codes, focussed on the research question. Ultimately, I resolved that failing to complete the thesis would be a worse representation of my participants' data and so decisions on which codes to proceed with needed to be made. This movement allowed me to produce a more manageable set of codes with which to start generating themes.*

### 2.7.3.3 Phase 3: Generating initial themes.

According to Braun & Clarke (2022), this phase involves engaging with codes to explore areas where there is potential similarity of meaning, clustering together these codes and exploring these initial meaning patterns. For Braun & Clarke (2022, p85) key questions to ask at this point are:

- "Does this provisional theme capture something meaningful?
- Is it coherent, with a central idea that meshes the data and codes together?
- Does it have clear boundaries?"

Potential themes were initially clustered using the Excel spreadsheet of codes. Each code was also written onto a post it note to so that codes could be physically moved into candidate themes. As recommended by Braun & Clarke (2022), visual mapping was also used at this stage to explore how potential themes might relate to one another. An example of an early visual map of themes is shown in Appendix I.

*Theme generation was also difficult for me. In my reflective diary I have written that I have not made many entries "because I have found the process so frustrating". Again, I struggled with the idea of excluding codes if they did not represent meaningful patterns across the data, or if they contributed to potential themes that did not address the research question. I leaned heavily on supervision at this stage and found my supervisor's support invaluable in sense-checking what I was doing, orienting me to the overall story of my research and for thinking about theme boundaries and relationships to other themes.*

### 2.7.3.4 Phase 4: Developing and reviewing themes.

According to Braun & Clarke (2022, p97), the purpose of this phase is to "review the viability of the initial clusterings and explore whether there is any scope for *better* pattern development". The aim is to check the scope and quality of candidate themes, but also to develop their richness and foster a nuanced, rich analysis that addresses the research question.

In this phase, codes were returned to, in order to check the appropriateness of their inclusion in themes. I also listened again to interview recordings, in order to glean whether themes had correctly captured what my participants had told me.

### 2.7.3.5 Phase 5: Refining, defining, and naming themes.

According to Braun & Clarke (2022), the purpose of this fifth phase of analysis is to develop themes further and produce more precise analytic work to refine the analysis. A core task in this phase is to write definitions for each theme, which they have described as effectively an abstract for each theme. A final list of themes with their component codes is shown in Appendix J.

### 2.7.3.6 Phase 6: Writing up.

In this final phase, the story of the research is created by weaving together the data analysis, interpretation and theoretical framework. The data familiarisation, reflective diary, field notes, coding and construction and refinement of themes together lead to the development of the final analysis (Terry et al., 2017).

*Braun & Clarke (2022) recommend against separately presenting the results of a study from the discussion as it tacitly echoes a model where the supposed objective* *findings of a study and what the researcher makes of them are considered distinct from one another, which is against the reflexive ethos of RTA. Whilst I accept this proposition, ultimately, I decided to separate my analysis and discussion chapters as this procedure is in line with how I worked in my previous career as a researcher in quantitative health psychology, and I felt that maintaining the structure I am used to would best enable me to tell my participants' stories. Further, although they discourage this practice, Braun & Clarke (2022) also acknowledge that for applied research, such as the current study, separating the analysis and discussion might provide greater clarity in terms of communicating the limitations, recommendations and implications of the study.*

### 2.8 Research Quality

In order to ensure the quality and credibility of the current research, the evaluative criteria proposed by Yardley (2000) were followed. Yardley's (2000) criteria describe key areas for qualitative studies to focus on to maintain quality: sensitivity to context; commitment, rigour, transparency and coherence; and impact and importance. Sensitivity to context is concerned with the how the researcher sets the scene for the research in terms of context and includes providing a comprehensive literature review, clear delineation of the philosophical underpinnings of the research, the balance of power between researcher and participants and ethical issues. Commitment refers to such aims as prolonged engagement with the research topic and aiming for skills and competence in the methods used. Rigour refers to the completeness of data collection and analysis and includes the adequacy of the sample size or collected data. Transparency relates to the cogency and persuasiveness of the account of the research; this can be supported by detailing all aspects of the analytic process, supported by an audit trail. Finally, impact and importance refer to the practical and theoretical value of the research project (Yardley, 2000). Braun and Clarke (2022) also provide a 15-point checklist for good reflexive TA (see Appendix K) that was adhered to in the current study.  The quality of the current research is discussed further in Chapter 4.

### 2.9 Chapter summary

This chapter provided the rationale for the methodological strategy including the ontological position of critical realism, and the chosen epistemology of pluralism. These choices were informed by the research question that aimed to investigate decision making and adherence to hydroxycarbamide in those with SCD from a relational perspective and helped to identify semi-structured interviews as an appropriate data collection method. The choice of RTA provided a pragmatic and flexible method of analysis that helped to answer the research question in this study.

## CHAPTER 3: DATA ANALYSIS

### 3.1. Overview

This chapter outlines the findings of the present qualitative study that used semi-structured interviews as a data collection method and reflexive thematic analysis (RTA) as the method of data analysis with attachment theory as the theoretical framework. Participants who took part in this study had a number of different conversations regarding hydroxycarbamide: some were not taking hydroxycarbamide, but were having conversations with their doctor where it was recommended they take it; others had made the decision to start taking hydroxycarbamide, but had experienced difficulties with side effects and subsequently decided to continue or discontinue taking; finally, one participant had started taking hydroxycarbamide, but struggled to adhere for reasons unrelated to side effects.

An RTA of the transcripts of eight interviews resulted in four themes, cumulatively containing a total of nine subthemes, as shown in Table 2. These themes and subthemes are discussed alongside extracts from participant interviews. In order to improve fluency, some extracts have been edited. Edits are indicated by '(…)'. Extracts were edited if they were of excessive length, or where sections did not contribute to the overall understanding of the theme (Braun & Clarke, 2022).

*Table 2: Themes and subthemes*

| Theme | Subtheme |
|---|---|
| Perceptions of vulnerability underpin the relationship | “The pain is a killer”, feeling vulnerable due to physical symptoms |
| | “A lot of people don’t know how to manage it” |
| Past relationships and templates impacting on the present | “My whole life I had looked to older people to help me make my health decisions” |
| | Unconscious templates in action |
| Maintaining independence | “From a very early age I spent a lot of time trying to understand how my body works” |
| | “I’m the one who is going to be taking their medication” |
| The adequacy of the response | “I don't think that there would be any reasons for him to recommend something that’s not good for me” |
| | “I need to see how it would benefit me personally” |
| | “As he continued to talk, I felt like he cared” |

*As mentioned in the previous chapter, I found the process of analysing the data quite challenging generally. However, I am more experienced in academic writing than I am with analysing qualitative data, and I found that through writing and editing this chapter I found it easier to hold my data in mind and shape the story of the analysis than I had previously. This may have been due to there being a gap in time of a few months between the end of my analysis and writing up, which may have provided me with some psychological distance.*

### 3.2 Perceptions of vulnerability underpin the relationship

This theme recurs throughout the data. To an extent, a sense of personal vulnerability can be viewed as underpinning the core relationship explored in this research. Logically, the participants in this research would not be interacting with these health professionals if they were not rendered vulnerable by their SCD and require some form of support or assistance from them. Precisely what their vulnerability was, however, was always individual, and often nuanced and participants seemed consciously aware of how their vulnerability meant that they were reliant on their healthcare professionals. This theme also explores the idea where there is a medical reality that those with sickle cell disease cannot often survive, let alone thrive without the assistance of medical professionals; they have a genuine need for specialist medical care.

### *3.2.1 "The pain is a killer", feeling vulnerable due to physical symptoms*

Participants' vulnerability is often recognised as an indelible part of their lived experience with illness; SCD is a painful condition and initial conversations about hydroxycarbamide were often conducted in the midst of acute, painful sickle cell disease crises.  An excerpt from Noah describing the circumstances leading up to his initial conversations about hydroxycarbamide illustrates this point:

> "Umm (clears throat) so I, I went in uh because of I felt like I was having some difficulties um I was having some serious complications um like I was starting to have acute chest pains, kind of (**OK**) and yeah, so I had to go in and get some checkups um and the I, I was getting these painful crises that that really forced me to go before our appointment date. So, so we talked about how we are going to maybe increase the number of times I go to visit him but he kind

> of said if the current eh, eh medications and management we are using a kind of becoming a little bit ineffective from time to time then there's something else he can recommend to me…” (Noah, 130–137)

Physical pain during crises can become unmanageable to the point of requiring hospitalisation. Noah’s description of the sequence of symptoms that ‘forced’ him to see his doctor before his appointment date also sounds like a crisis in the broader sense of the world, whereby his physical health seems to be really and painfully deteriorating, and in need of medical support. The intensity of these SCD symptoms is further suggested by Eileen in her description of the pain she experiences.

> “so it's not just a matter of managing the pain, is managing the sickle cell disease so that the pain doesn't come as often, so you don't need to then manage the pain, because the pain is a killer (…) oh God, it is tough (**hmm**), it's, it is very tough, umm, I don't think there's any other pain on this earth that, you know, supersedes that” (Eileen, 568–574)

Participants’ core need underpinning their relational experiences with healthcare providers could also shift, however. Many of those who took hydroxycarbamide experienced significant side effects, which in themselves could be distressing. For example, Vanessa talked about how her doctor had encouraged her to take hydroxycarbamide as it would improve her quality of life:

> “(…) the doctor said if I give this one a try I’ll stop being more sickly and also it would like, reduce the number of times I will be required to go to the hospital or the number of things that I'm supposed to do to be OK” (Vanessa, 144-146)

However, her experience with the medication itself soon became her cause for concern. She describes pain as well as visible manifestations of physical decline attributed to her taking hydroxycarbamide, which must have been extremely frightening:

> “(…) I developed fever, sore throat, uh also the, if I, if sometimes I go to a cut like, I needed to, it led to a lot more bleeding, or the bruising was common, the bruising was more possible and there was more likelihood of getting bruised (**OK**) and also the (.) stomach pains, yes, those are the side effects…” (Vanessa, 50-53)

Vanessa described her experience of the side effects of hydroxycarbamide as “*intense*” and started to fear that the treatment itself might be causing her damage.

> “because it was at the beginning, so I thought something was bad or something was going wrong with the medication and how my body was responding to the, the hydroxy”. (Vanessa, 78-80)

This intensity of symptoms was not a universal experience, however. For some, conversations about hydroxycarbamide occurred with a sense within participants that their SCD was well managed and under control. For example, Aidan experienced few symptoms and rarely went into hospital:

> "(…) you know, I don't go to hospital that often and I, I don't, I think there was one point I think it was every three months, then they said maybe it's not really beneficial for me for every three months because of how I manage my condition, and it was every 6th [month]…" (Aidan, 180-183)

With regards to the research question, what is important to remember is that conversations about hydroxycarbamide occurred within the context of each participant's individual perceptions of vulnerability. For example, for those with clear, unpleasant symptoms that are attributed to SCD, hydroxycarbamide can be understood as an appropriate solution. For others who feel that their SCD is being well managed, hydroxycarbamide was sometimes recommended in response to a problem that is not perceived to exist.

### *3.2.2 "A lot of people don't know how to manage it"*

Further heightening participants' vulnerability was an awareness expressed by many that SCD was an extremely serious condition, which has the potential to lead to premature death if not managed cautiously and correctly. When participants spoke about a lot of people not knowing how to manage their illness, they were referring to a perceived deficit in knowledge about SCD in many of the healthcare professionals that they encounter. This idea was expressed cogently by Eileen when she was discussing how it was difficult to talk generally about triggers for crises in SCD, as the disease manifested itself differently in everyone:

> “you know, we all have different triggers, like I said, em so I can't just look at somebody and say ‘ohh he's done this so I can do it too’, well, that would be, what might kill me, you know what I mean?” (Eileen, 561-563)

Participants also spoke of how SCD can also be a relatively rare condition, necessitating specialist knowledge on the part of healthcare providers. Listening to the participants, it seemed that the seriousness and relative rareness placed a particular emphasis on *who* those with SCD are treated by. Many participants seemed cognisant of being reliant on their doctors or other healthcare professionals to survive. When I asked Riley and Noah (respectively) to describe their relationship with their doctor, they responded:

> “I would say it's a kinda close friendship (**yeah**) it's just a friendship (**yes**) whereby it's like a I have my life in his hands (…)” (Riley, 231-232)

> “ […] this is somebody you are kind of entrusting, let me say entrusting your life, your health in [them]…” (Noah, 274-275)

One can see how this scenario raises the stakes for the relationship between the person with SCD and the healthcare providers they encounter. At times it felt that participants were aware of this, which could make them wary of dealing with healthcare professionals as they feared that they might lack sufficient knowledge to take care of them. For Ivy, this was based on her own experience of being in crisis in hospital, and being asked by staff how to care for someone with SCD:

> “(.) Uhm. I think a lot of, a lot of people don't know how to manage it and what sickle cell is when you when you're having a crisis like the, because I know people have different treatment plans but I did have a lot of people come up to me and ask me ‘oh, so what’s sickle cell’, like nurses being like: ‘So what do I need to do?’” (Ivy, 335-338)

Similarly, for Aidan, this lack of specialist knowledge seemed to lead to a sort of anxiety whereby he was forced to take matters into his own hands because it could not be guaranteed that medical staff would be able to treat him:

> “So, I feel like when you have a rare condition, you kind of have to become the master of your own care because you can't guarantee going into the hospital, they'll know how to treat you, like that's (yeah) that's just the reality of things um so yeah” (Aidan, 589-592)

Cumulatively, this first theme highlights that the stakes are extremely high for the relationship between those with SCD and their healthcare staff, and participants seemed aware of this. Not only was there typically a genuine medical need to be met, but also a sense that need could not be met by just anyone; there was a need for someone special, with specific knowledge about SCD, who could be trusted to hold their lives in their hands. Conversations about medication, whether at the point that hydroxycarbamide was being recommended, or later when side effects were being experienced took part with this important background colouring how these conversations were experienced. This will be discussed further in the second subtheme of Theme 2, below.

## 3.3 Past relationships and templates impacting on the present

The second theme explores the idea that past experiences of relationships in the healthcare setting, and unconscious templates of relationships that participants carry with them from their personal lives impact on their relationships with their healthcare professionals and their experiences of interactions with these professionals. Again, conversations about hydroxycarbamide occurred within this context, those with SCD often seemed to be relating to their doctors whilst inhabiting roles that could impact on how information about this medication was received and responded to.

### *3.3.1 "My whole life I had looked to older people to help me make my health decisions"*

The first subtheme explores how previous relationships can impact on participants' current relationships with their healthcare professionals through the establishment of conscious roles and responsibilities. As SCD is a lifelong condition, participants' first dealings with healthcare providers were often as children. A common experience amongst participants was that their parents were primarily responsible for all aspects of their healthcare throughout childhood, including the decision to take hydroxycarbamide and subsequent adherence. As a result of these experiences, participants assumed roles and responsibilities that were appropriate for these circumstances, but potentially created difficulties later when they became adults who were responsible for their own care.

As an example, Ivy described how she had started taking hydroxycarbamide as a child and unfortunately struggled with serious side effects as she entered young adulthood. Despite how ill she felt, and her strong feeling that it was her medication that was making her feel ill, she continued to take hydroxycarbamide for a significant period of time because her doctors felt it was the right course of action. When I asked her whether she was comfortable putting her trust in them, she told me:

> “I think yes, because my whole life I had looked to older people to help me make my like health decisions (**yeah**) like relying on my mum and then like relying on doctors and just cause, for me it’s that I know they know more, that I know they'll do what's best…” (Ivy, 241-244)

Several participants seemed to speak of a sort of deference to doctors’ authority, which could have clear implications around autonomy in decision making around medication. For example, Vanessa said the following when I asked about why she adhered to her medication:

> “Because I'm supposed to follow the doctor's instruction and the prescription (.) and I believe in doing the right thing” (Vanessa, 266-267)

Finally, others had experienced difficult encounters with doctors in the past, which fed then into how they subsequently related to healthcare professionals or interpreted their medical encounters. For example, previous experiences of doctors as uninterested or uncaring, led them to anticipate the same going forward, occasionally adjusting their behaviour accordingly. As an example, Aidan spoke of having had an excellent relationship with his hospital consultant when he was young:

> "I feel like, I mean, I had a very, I guess I had a very unique experience when I was younger in that one of my doctors really took an interest in helping me (…) and like so it was very much caring about me beyond just um like my sickle cell situation" (Aidan, 152-158)

Unfortunately, in adulthood, things were different, which changed how he approached his interactions with the hospital. I got a strong sense from Aidan that his great experience of relationships in healthcare as a child really informed his expectations as an adult. Unfortunately, these expectations were not met, and as a result Aidan seemed disappointed by the quality of his healthcare in adulthood. In response, it seemed that his experiences, particularly of seeing different doctors each time he attended the hospital, hardened him, and taught him that he could only rely on himself. When discussing his experiences in his outpatients' appointments, Aidan said:

> "I have to be able to come with questions and come with eh interest in my own health, because otherwise it's just going to be a tick box exercise" (Aidan, 422-423)

Aidan referred to a "*tick box exercise*" at several points during our conversation, which was his stereotyped description of his experiences in healthcare situations in adulthood, whereby the aim is for the healthcare provider to be able to demonstrate that they have covered the necessary agenda from their perspective, as opposed to trying to get alongside the SCD patient, to see what their concerns might be. For Aidan, his disappointment and lack of faith in the system also directly impacted upon how he experienced the recommendation to take hydroxycarbamide:

> “As in like being treated so badly in the past, it makes it hard to then trust going forward, um that you will be treated correctly or the treatment that they're giving you is the right one for you specifically, um which is also why I guess the hydroxyurea works for everyone spiel doesn't really sit well with me” (Aidan, 630-633)

### *3.3.2 Unconscious templates in action*

In other cases, participants’ experiences of relationships with doctors when discussing hydroxycarbamide seemed to function based on unconscious templates, whereby the relationship with their doctor was not experienced as a *secure base* from which their needs could be met. Returning again to Elissa, she described how for a long time she lied to her doctor about taking her medication:

> “(.) mmm just because, I guess when the question comes ‘have you been taking your medications?’ Uh I will say yes just to avoid the conversation of going ‘why would you not take it?’, ‘Why would you not do that?’ this and that, I guess just to avoid the bigger conversation of the why you don't you take it, I guess” (Elissa, 296-299).

In this instance, it appears that Elissa did not tell the truth about the fact that she did not strictly adhere to her medication regimen to protect herself from potential negative consequences, in the form of a “bigger conversation” about why. Listening to Elissa, it seemed that she experienced her relationship with her doctor as anxiogenic; she seemed to expect to be punished for not taking her medication, inhibiting her ability to discuss her adherence openly. Later, once she realised that this was not going to happen, she seemed surprised that she could reveal this to them, and not be rejected:

> “(…) so they understood [why I was not taking my medication], and then they said that they, their job is there (.) for them to take care of me and all that, to give me support , uh so it was difficult conversation, but really helped, really umm helpful, no that’s not, that’s not the word, umm, he was (.) umm (.) I guess (.) reassuring to know that they, they, they understood and they would take care of me anyway” (Elissa, 263-268)

I also wondered when listening to Eileen speak about how she interacted with her consultant at her haematology department whether she was also being guided by an unconscious template. She spoke to me about how she almost seemed to agitate when in the presence of her doctors. I had a sense that this was what she felt she needed to do, in order to ensure that she would be cared for:

> Eileen: “…I think the patient should be at the centre of, of the care”
> Interviewer:” and and I, well, I take it from that, you don't feel that you're at the centre of your own care?”

> Eileen: “eh well, I feel like I am because I, I demand and I, you know challenge and I, you know, do a lot of, of that…” (Eileen, 307-311)

When she was advised to start taking hydroxycarbamide, she didn’t calmly accept or reject, rather drew her consultant into a lengthy engagement:

> “for me it was all about “You must get on hydroxy”, “You must get on hydroxy” you know, like why? Why? Tell me why? You know, “but it’ll make your life better” right no (…), so I kept on saying no, I mean, you haven't given me enough to convince me…” (Eileen, 188-195)

It must be noted that a number of participants also had experiences where their relationship with their medical professionals appeared secure, comfortable and unproblematic with regards to the key functions of the doctor-patient relationship. Often this seemed linked to their doctor being perceived as *professional*, and adhering to a template from which comfort could be derived. For example, when I asked Vanessa how she would describe her relationship with her doctor, she described it as “*consistent, professional, helpful, all that” (*Vanessa, 213*).* In Vanessa’s mind, seeing these qualities in her doctor appeared to be a source of comfort:

> “it's important to me because I need to be in, let’s say in good condition, in good health (.) hmm I think it’s important (.) because at least having someone you can rely on, you won’t have, I think they’ll be there for you when you need

> them and in case of emergency, they are going to be there too” (Vanessa, 226-229)

Her use of the phrase “in case of emergency” suggests that her doctor evokes in her a sense that they will be able to protect her and keep her safe, even in the most serious of circumstances.

Taking comfort in doctors’ professionalism is likely particularly pertinent for those with SCD given the vulnerabilities discussed above, along with the knowledge in many participants that special skill and knowledge is needed to treat SCD. Indeed, being knowledgeable was commonly cited across many of the participants when they discussed valued attributes of their healthcare providers, for example when I asked Elissa how she would describe her doctor, she said:

> “Really nice to, yeah nice, umm, it's a woman, umm, umm pretty nice person (…) really knowledgeable and (.) just [a] really nice person” (Elissa, 450-451).

Similarly, Noah described the importance of his doctor’s knowledge as follows:

> “I felt he was supportive um and knowledgeable, which is crucial, really crucial in managing and optimizing treatment outcomes” (Noah, 234-236)

It is worth noting at this point that some of those who spoke about having had negative relational experiences with their doctors, at the same time were reluctant to explicitly criticise them. Taking the example of Ivy, having discussed the process whereby she felt her difficulties with taking hydroxycarbamide were not listened to leading her to experience significant stress and discomfort, I asked her how she felt about her main consultant. She told me:

> "Em I'm not the type of person to, like, hold any negative opinions of anyone, like I think there's things that she could have done better, there's things that even I could have done better" (Ivy, 625-627).

A similar pattern was also suggested in Aidan and Eileen's conversations with me. Both participants, having expressed their disappointments in how they had been treated during their lifetime, were also quick to empathise with their doctors, in effect downplaying their own difficulties because they were aware there were also difficulties on the other side. They told me:

> "it's like I I try not to like bash the medical system too much because I can only imagine how much they have to deal with um on a daily day-to-day business" (Aidan, 439-441).

> "I guess it's again maybe through no fault of theirs (…) they're all overworked so for us patients as well, sometimes we feel guilty even you know, sometimes to, to email them and you know, I don't want to sound as if I'm complaining because I understand their, their situation as well" (Eileen, 691-695).

It is possible that these assessments of each situation represent a mature, realistic evaluation, possibly reflecting a balanced sense of personal and shared responsibility. However, I also wonder whether for a person who is vulnerable, being critical of those on whom you rely for care might represent a risk and thus another attachment strategy, of burying critical and wounded feelings in order to preserve a needed relationship, might also be evident here.

In summary, when speaking about hydroxycarbamide with doctors and other healthcare professionals, participants seemed to both carry expectations from previous encounters with medical staff into the encounter, as well as unconscious templates based on previous relational experiences. However, and perhaps crucially, it does not appear that either conscious expectation of roles and responsibilities, nor of the experience of unconscious templates are set in stone, and that experiences with their doctors could lead participants to reassess these relationships. This will be discussed in further detail below.

### 3.4 Maintaining independence

This theme explores how participants' deep knowledge of their own bodies and of how sickle cell affects them was also an important factor in many participants' relationships with their healthcare providers and encounters where medication was discussed, along with a strong sense, not incorrectly, that regardless of how they related to their doctors, they were the ones who were ultimately responsible for making decisions as they were ultimately the ones who would be impacted by any decisions made.

### *3.4.1 “From a very early age I spent a lot of time trying to understand how my body works”*

Several participants spoke about having detailed models of understanding of how SCD impacted them personally. Participants spoke of how they understood what caused them to have crises, what they needed to do in order to keep themselves well and what they did and did not require in terms of treatments for their SCD. As mentioned above, at times this was linked to participants’ previous experiences with healthcare providers, which led them to believe that they had no choice but to learn about themselves, or similarly because of their sense that SCD is a rare disease, and they cannot guarantee that they will encounter medical professionals with sufficient knowledge to treat them.

One important corollary of this deep self-knowledge was that any new information introduced about medication by their healthcare providers was actively compared to these personal models. As discussed above, Aidan’s awareness of having a rare condition, along with some disappointing healthcare experiences, seemed to lead him to conclude that he needed to take responsibility for his own health, perhaps as he did not feel that he could rely on anyone else to take care of him. When hydroxycarbamide was suggested to him as an option, his personal disease knowledge, and sense that he had his SCD under control doing what he was currently doing, made him query whether hydroxycarbamide would be of any benefit. Thus, Aidan relied on his own model of understanding for his SCD when receiving the recommendation to take hydroxycarbamide, not his doctor’s.

> “I was in a position where I felt like I don't get crisises [sic] that often, and I usually know the reason why I get a crisis, um, so it was, so for me it felt like,

> OK, it's nice to have an option should my crisises [sic] get worse (**yeah**) but apparently then it's, it's, it's manageable in my perspective and like I haven't had a crisis in some time so it kind of yeah, it just made me feel like it, if it, if what's working currently is working (**yeah**) and I don't want to take something that might interfere possibly" (Aidan, 51-57)

Eileen also felt that she had worked hard to understand her SCD, to the extent that she was aware that others with SCD were likely less "*astute"* in their own understanding that she was. Eileen appeared to utilise her self-knowledge differently to Aidan, however. Aidan appeared to use his self-knowledge to critically evaluate the information he received from his doctors, whereas Eileen saw such knowledge as meaning that her clinical team would be in a better position to help her, if she knew and understood herself.

> "So you know, em from a very early age I, I, I, em, I spent a lot of time trying to understand how my body, umm, you know I guess works with or reacts to the, the, the sickle cell and, and I've managed myself that way (**yeah, OK**) try to help my, my clinical team help me, you know, umm manage my situation better" (Eileen, 161-164)

Although for Aidan and Eileen, their self-knowledge and understanding was broadly experienced as empowering and beneficial, for Ivy it was a source of conflict. She talked about being aware that hydroxycarbamide was not working for her, that it was making her feel so ill that she was unable to take it, further worsening her condition, but felt unable to articulate this to her healthcare providers and effect change. I asked Ivy why she continued to take her medication, even though she was aware that it was making her feel ill. She told me

> "Because I had no other option at that time I think, because part of me, a part of me, I did like to have certain times where I would take it and then certain times where I wouldn't because I knew that for it to work, you have to consistently be on it (**yeah**) so I knew at certain times I was like, if I can't take it, I won't take it, but then I did have certain times I said I can let me actually try and get back on this and see if I can like do it" (Ivy, 401-406)

When I asked Ivy why she continued to take hydroxycarbamide, even when she was aware that it was not working for her and making her ill, she told me:

> "em (.) I think because I had my trust in the doctors, like, I kind of just left it on the back burner and I thought when I next see them, we'll like speak about it (yeah) but then it kind of never really moved anywhere for like a year" (Ivy, 409-411)

Thus, whilst self-knowledge appeared to be a significant variable influencing the experience of interactions regarding hydroxycarbamide, its impact on the outcome of those interactions appeared to be moderated by other factors, particularly conscious and unconscious models of prior relationships.

### *3.4.2 “I'm the one who is going to be taking their medication”*

Other participants expressed an awareness that, although their healthcare providers played a vital role in their wellbeing, ultimately responsibility for their health rested with them, not least because they were the ones who would be impacted by any decisions made about which medicine to take. From a relational perspective, this seemed to suggest a certain dilution of the advice and recommendations given by healthcare professionals about medicine. For many participants, even under positive relational circumstances, participants seemed to hold something back in terms of completely allowing themselves to defer to their doctors’ word, instead holding themselves ultimately responsible for decisions.

For example, Catherine, who had a good relationship with her doctor, spoke of how although she trusted her doctor and accepted her doctor’s recommendation of hydroxycarbamide, she still planned to speak with others and do her own research prior to taking the medicine. For Catherine, her trust in her doctor was present, but not absolute, ultimately she seemed to express that she would ultimately be the one to take any decision.

> Interviewer: “OK. So when he says, I think that it's a good idea for you to take this medicine, by the sounds of it. Then you trust him and you think, OK, this must be a good idea then”
> Catherine: “Yeah”
> Interviewer: “Yeah. OK. And then so yeah, so this is kind of the decision was it how was it then to, was it difficult to make the decision to take it or back in when you were 20?

> Catherine: (.) yeah, it was kind of difficult because I'm the one who is going to be taking their medication (**yeah OK**) so I have to get other people's opinions and advice, yeah" (Catherine, 178-187)

*In hindsight, I have wondered whether I could have probed more here to explore the types of research participants might have done, or other opinions they might have sought when considering whether to take hydroxycarbamide. Such probing could have yielded valuable information on what they were hoping such additional research would provide them. For example, might they have valued real-life experiences of others taking the medicine more than their doctor's opinion, or were they looking for reassurance from other trusted sources that their doctor could not provide. My memory from the time is that I had considered unpacking this with participants, and had I been speaking with participants in my capacity as a trainee counselling psychologist, committed to valuing their subjectivity, and non-hierarchically allowing them to also determine the direction our conversation went, I may have done so. However, in my role as a researcher focussed on the aims of the study, I felt more interested in their relationship with their immediate healthcare provider, particularly with regards to the extent to which they trusted them, and thus felt such probing might have been beyond the scope of my study. These tensions were not always comfortable, however, as described in Section 2.6.1, the pressure to ensure that a piece of work of sufficient quality was produced that would allow me to complete my doctorate was often a deciding factor in determining which way to proceed.*

Riley reported a similar experience, whereby she had a good relationship with her doctor, and yet decided that she would do her own research prior to taking the medicine. When I asked her about her experience of taking hydroxycarbamide, she told me:

> “when the doctor was talking about introducing the drug, uh of course he talked of the side effects and eh also I did research on the drug because er I wanted er to put myself on something that was not going to harm my health” (Riley, 56-59)

For Elissa, who had started taking hydroxycarbamide as a child and thus was not actively involved in this initial decision, conducting her own research into the medication that she was putting into her body seemed to be part of the process of becoming an adult, she told me:

> “Umm but I didn't really umm research about it [when I was a child], just took it, but then as I grew older I research about it, I saw that it’s um quite a quite powerful medication and all that, so I became more aware of what I was taking, I was taking with the becoming an adult process” (Elissa, 104-107)

In summary, although participants were often vulnerable in some way and had an acknowledged need for their relationship with healthcare providers to address and carried conscious and unconscious models of relationships into conversations about medication. Often, participants seemed also to maintain a sense of self in these interactions, either through their own model of understanding for SCD, or through awareness that they held ultimate responsibility for both taking medications as well as for the effects of any medication.

### 3.5 The adequacy of the response

The first three themes have essentially focussed on intra-psychic relational variables within those with SCD. The final theme is more concerned with the inter-psychic dynamic between doctor and patient. To an extent, it concerns how effectively the aspects of participants relational thoughts, concerns and tendencies discussed in the first three themes are responded to by medical staff. It seems that these responses, or perhaps more pertinently, the person with SCD's *experience* of these responses, are likely crucial in determining the outcome of interactions regarding medication use with regards to initial decision making and subsequent adherence.

#### *3.5.1 "I don't think that there would be any reasons for him to recommend something that not good for me"*

The first subtheme explores the participants' experience of feeling held in mind by their doctor over time. Trust appeared to be an important factor here; participants who had an established relationship with their doctor, who they felt to be medically competent and to know their medical history, appeared to have their concerns about their condition contained by this relationship; when hydroxycarbamide was suggested as an option, participants appeared more likely to accept the recommendation, because they trusted that their doctor had their best interests in heart. When side effects caused them to waver and challenge adherence, their doctors were also able to contain these anxieties and make it easier for them to persist, relief was experienced when solutions to concerns were offered.

An important aspect of this sub-theme is the idea that some participants saw the same doctor regularly, sometimes maintaining relationships from childhood; this in and of itself appeared containing and to bring comfort to participants. For example, Riley spoke of having had the same doctor “*throughout her life*”. In Riley’s mind, her doctor’s deep and thorough understanding of her medical history meant that they were uniquely placed to be able to offer her medical advice:

> “he had been the one taking me through the situation throughout my life since (.) childhood and I had trust in him so I didn't think of changing the doctor, (…)he is the one who understood my health history, so I believed in him and I knew that ah you know when, when, when I was taking the test, sometimes and eh also when he was checking the progress he understood my body, understood my immunity and ah I knew it could I could he was the only one who could advise better” (Riley, 155-163)

This contrasts directly with other participants who spoke of not knowing who they would see when they went to hospital. This was often experienced as stressful, or as making the whole medical experience feel unappealing and uncaring. For example, Aidan told me:

> “(…) every time I do go into the outpatients, it's a different, It's a different doctor that I'm seeing, so there is no relationship or rapport umm (yeah) with the person that I get (…), so it's like I have to kind of explain how I'm managing my condition yet again to a different face (…) , it just felt very much like ‘oh, you've read my notes, you know me’ kind of situation whereas now,

> almost my most recent experiences have just been (.) ‘oh, we haven't seen you in a while’ or something like that, ‘oh, you haven't been hospital and that's great, keep it up’ and then (yeah) that's part of it” (Aidan, 131-147)

As well as the experience of being held in mind being central to some participants relational experiences, it also seemed important for some that their doctor was able to contain any anxieties they had about their medication, or their illness more broadly. Vanessa described to me how she went to her doctor when she started taking hydroxycarbamide because she was having serious difficulties with side effects, to the extent that she wanted to stop taking the medication. Her concerns were taken seriously by her doctor, who ran some tests, and based on the results told her that she did not need to stop taking hydroxycarbamide. Vanessa told me:

> “(…) I was worried before going to the doctor. I was just worrying. I have nothing to show me that I need to stop taking these medications. I'm just worrying. And (.) OK, let's go into the doctor, at least he has something he has analysed and he has something to show me that this is not as bad as you think (.) yes” (Vanessa, 201-205)

Thus, based on her interaction with her doctor, Vanessa went from having real concerns about her health, to feeling that she was “*just worrying*”. It seems, that by taking her concerns seriously, and by conducting his investigations, her doctor was able to digest Vanessa’s fears and show her “*this is not as bad as you think*”.

Noah similarly went to his doctor in his early days of taking hydroxycarbamide concerned that it might not be working as planned. In response to this anxiety Noah told me that he went to speak with his doctor:

> Noah: “I wanted some, some confirmation from the doctor and I was also, you know it, I was also worried, you know, it must just be that feeling of, I, that kind of, how can I say, that the feeling maybe of feeling better was (…) in my mind and not realistic. So I wanted just confirmation that yes it's working, it’s good, you are starting to improve”
> Interviewer: “And then how did that appointment go?”
> Noah: “Uh, the doctor kind of confirmed like, ohh yes uh, things are good, things, things, things look good, so I felt better and I felt also convinced”
> (Noah, 323-330)

Crucially in these examples, through containing Vanessa’s fears about her side effects, and Noah’s concerns as to whether his medication was having any beneficial effects, their doctors were able to ensure that they persisted with their use of hydroxycarbamide.

Unfortunately, an alternative experience was also had by others, whose anxieties and fears were not contained. Participants reported feeling lost and fearful or that their medical staff did not know how to treat them. Conversations about hydroxycarbamide sometimes occurred within this context, with participants feeling like the medicine might make things worse rather than better or questioning their doctors’ motives. Some participants reported feeling agitated during consultations, wrestling with their doctors, finding it hard to take in information and reporting that the consultation room did not feel like a safe space.

As was discussed earlier, it is possible that this was due to unconscious models of relationships taken into interactions by participants, equally, we can conceivably think of this as a failure of medical staff to calm patients, inhibiting their self-regulatory capacity. For example, Ivy talked about feeling so stressed during her interactions with healthcare staff that she was unable to take in the information that she was being told:

> “when I was, like, trying, changing from when I was a kid to being more of an adult. It was kind of a em stressful time (…) it was kind of like I was across seeing a lot of people (**yeah**) and then dealing with having sickle cell and even just the accepting it part I really struggled with (**OK**) so when it came to taking in information I found I didn't take it in like really well” (Ivy, 107-115)

### *3.5.2 “I need to see how it would benefit me personally”*

The concept of misattunement, in other words, medical staff lacking a shared understanding with participants of their wants and needs also seemed present and important in the data. Listening to the participants, it seemed that at times that they seemed frustrated, anxious or disappointed when this shared understanding was absent, both in terms of having your individuality recognised, sometimes linked to their intimate knowledge of their own disease, but also having their core vulnerability recognised and responded to.

For example. Aidan told me the story of how hydroxycarbamide was recommended to him during his six-monthly general check-up in outpatients. He told me that his consultant said to him that they had seen it work for the majority of patients, and that he received “strong encouragement” to take it. As mentioned under Theme 1, Subtheme 1, above, Aidan felt that he was managing his SCD well. I had a sense from Aidan that he felt disappointed at how the conversation went with his consultant, as he told me how he would have preferred it to go.

> “I would have rather it was said in terms of like “your crises are becoming more frequent, um this is an option for you to take”, whereas it was more like “OK, that's great that you haven’t had a crisis in ages, but then there's medication you should take all the time”. So it (**yeah**) just yeah, it just, I think it could have been delivered in more of a specific to the patient approach as opposed to: all sickle cell patients, everyone on hydroxy” (Aidan, 100-105).

Eileen had a similar response to being recommended to take hydroxycarbamide. She talked of comparing her own personal blood results with what would be expected from taking hydroxycarbamide and arguing with her consultant that her results were already above what would be expected from taking the medicine. I almost had the impression from speaking with her that she was insulted to be offered something that appeared to have no relevance to her, accusing her doctor of making the offer “because that’s what the book says”.

> “I feel like I'm stressing my body [by choosing to take hydroxycarbamide] a lot more just for the sake of taking a, you know, a checkbox because you have one more person on your list who is on the hydroxy. So that was my attitude to it, umm, that I need it to see how related to me personally it would benefit

> me (…), so when you're selling something to somebody, it's not just “oh take it because it will make it better, because that's what the book says”” (Eileen, 216-226)

In contrast, being seen for who you are and known medically by someone you trusted at times appeared to be a source of comfort, making it less likely that a medication would be doubted and easier to cope during a period of illness or discomfort. For example, for Vanessa, who had the same doctor for several years, derived comfort from having a doctor who knew his medical records and status intimately, and so would be able to spot any difficulties as they arose.

> “Because he (.) have the records, my records and I believe that he monitored me, me in my blood tests and everything from the start is a good, a good thing, (.) like the consistency (…) because if a change maybe happens, he would be able to realise it” (Vanessa, 111-117)

### *3.5.3 “As he continued to talk, I felt like he cared”*

The third and final subtheme explores the idea that for many participants, the actions of healthcare professionals were crucial in driving the results of encounters. Although participants might enter encounters with conscious and unconscious models of relationships, needs and preferences, how their medical staff behaved towards them were also important determinants of their relational experiences. For example, even though Ivy generally did not have great relational experiences with her healthcare staff, she still experienced significant relief at the moment when she felt that her doctor had finally taken steps to change her treatment plan. When I asked Ivy how that felt, she told me:

> “eh, kind of like a relief because I was thinking I can get my health under control, I can not think about, like, the worries I’ve had (…) I was anxious quite a lot thinking about the future and just having that news made me think, OK, maybe I can, like, kind of, live, like a more normal life, like when I was a kid and I had, when the hydroxycarbamide was working for me” (Ivy, 454-471)

For some participants, their experience of how their doctor acted towards them helped them to see that the relationship was different to that which they expected. Through their doctor’s actions, they were able to appreciate the relationship in reality, compared to being filtered through previous conscious or unconscious templates of relationships as were discussed above. The experience of the relationship in reality appeared to have a positive impact both on the initial decision to take hydroxycarbamide, and for persevering with hydroxycarbamide once initiated. For example, Noah spoke about how he was initially suspicious when his doctor recommended hydroxycarbamide to him. This changed, however, as he spent time with his doctor, listening to him speak:

> “I was thinking like he’s just recommending it for the sake of recommending (…) For giving me some hope maybe that maybe I will get better and stuff like that. But as he continued to talk, I kind of like, felt like he cared, and he was recommending this because he wanted me to get better so that maybe he can feel an achievement as a doctor” (Noah, 180-184)

For Riley, her doctors' responsiveness and attentiveness when she was experiencing "*tough*" side effects for the first time, both in preparing her by letting her know in advance what to experience, and whilst she was in the midst of discomfort, seemed crucial in encouraging her to continue taking the medicine.

> "em at first ah as I had said earlier, I had some side effects which were a bit tough (**yeah**) you know (…) (**mm-hmm**) things are the doctor had talked to me and I was ready for it and I was informed I decided that I was going to continue and I also I was visiting the doctor as I was taking the drug (mm-hmm) check on how I was moving on with the drug check on how my body was responding to the drug and eh to him, it was normal for it to respond that way because it a new drug (**yeah**) and eh so he continued encouraging me and that uh, of course, advice on some of the meals I was to take and eh some other drugs that I was going to take along with it (yeah) that that helped me to overcome the side effects" (Riley, 119-128)

In summary, participants appeared to benefit from being held over time in mind by someone that they felt they could trust and who they felt contained their anxieties about their illness of side effects for their medication. Participants also spoke of the impact of a misalignment between their understanding of SCD and their doctors; this seemed to be particularly important when hydroxycarbamide was initially offered. Finally, this theme also highlighted the importance of *how* the healthcare provider behaves towards those with SCD and that this behaviour could at times participants to reassess their original thoughts and feelings.

### 3.6 Chapter Summary

This chapter presented a report on the RTA of interviews addressing the research question, providing interpretation and analysis of the four themes and nine subthemes. These findings will be discussed in greater detail in the next chapter.

# CHAPTER 4: DISCUSSION

## 4.1 Overview

This chapter discusses the findings of the current qualitative study that used semi-structured interviews as a data collection method and reflexive thematic analysis (RTA) as the method of data analysis with attachment theory as the theoretical framework to examine how those with SCD who have been recommended to take hydroxycarbamide experience their medical encounters where the medicine has been initially recommended and where hydroxycarbamide is monitored over time. Findings are presented in relation to the research question and existing research evidence, theoretical and clinical implications are discussed along with a critical evaluation of the present study. Finally, some ideas for future research are suggested before ending with some overall conclusions for this study.

## 4.2 The findings and the research question

This study aimed to examine how those with SCD who have been recommended to take hydroxycarbamide experience their medical encounters where the medicine has been initially recommended and where hydroxycarbamide is monitored over time. Four themes were developed containing nine subthemes. The purpose of this section is to contextualise the research findings, and to consider the findings alongside existing research.

### *4.2.1 Discussion of Theme 1: Perceptions of vulnerability underpin the relationship*

This theme directly speaks to the research question, as each core concern or relational need reflected in their vulnerability provided important context to interactions with doctors where hydroxycarbamide was addressed; were it not for their vulnerabilities, there arguably would be no reason for the interaction between them and the healthcare professional.

Further, and as will be described under the discussion for theme four, below, participants' vulnerability poses the question that it is incumbent upon the doctor or healthcare professional to answer. It seemed crucially important for healthcare professionals to notice and address the individual and nuanced vulnerabilities expressed by participants in order for these interactions to be effective.

From a theoretical perspective, suffering from physical symptoms, either attributable to SCD or to the side effects of hydroxycarbamide can be perceived as a threat, causing the vulnerable person to activate their attachment behaviour system (Bowlby, 1977). This in turn can lead to the seeking of proximity to an attachment figure; indeed, participants often seemed consciously aware of how their vulnerability meant that they were reliant on their healthcare professionals.

In line with this, this theme also explores the idea where there is a medical reality that those with sickle cell disease cannot often survive, let alone thrive without the assistance of medical professionals; they have a genuine need, not simply for medical care, but for *specialist* medical care. This nuance seemed to place a particular weight on *who* participants were treated by, since one needs specialist skills and knowledge to be able to handle it correctly. With regards to the research question, this suggests that when medication is being discussed, the *who* is talking is as important as *what* is being talked about.

Similar concerns about the professional competence have been reported in previous research with those with SCD. A mixed-methods study conducted in the USA that administered surveys to 208 individuals and conducted 44 in-depth interviews (Phillips et al., 2022) examined barriers to care in those with SCD.

Participants in the study reported that health care providers often did not seem to have sufficient knowledge of SCD. Other studies have also reported that a lack of knowledge about SCD in staff was amongst the most consistently reported patient-reported barriers to pain management in SCD (Bemrich-Stolz et al., 2011; Haywood Jr et al., 2009).

Similar findings have also been reported in the UK. Qualitative research with young people in England also found that non-specialist staff are perceived as not knowing enough about SCD, and that this serves as a barrier to attending hospital for non-specialist care (Renedo et al., 2020).

Further, the activation of attachment systems also makes relevant *how* those with SCD are responded to by their doctors. The response received by the person in distress, in the form of an attachment figure who is available and responsive, can serve to deactivate the attachment system. If this does not happen, depending on the internal working model, deactivating or hyperactivating attachment strategies may be employed (Hunter & Maunder, 2015), as will be discussed in further detail in the next section.

### *4.2.2 Discussion of Theme 2: Past relationships and templates impacting on the present*

This concept explored in this theme seemed to directly influence initial decision making and later adherence. Whether consciously, through their previous lived experience in the form of roles and expectations of doctors and patients, or unconsciously, through internal working models of relationships or transferential experiences, participants experienced their interactions with their doctors in a personal, nuanced idiosyncratic manner. Thus, suggesting that information regarding the decision to take or adhere to hydroxyamide will also have been received in a non-standardised way.

The lifelong nature of SCD appeared to be an important factor here. SCD is an inherited condition which is often diagnosed at birth; the UK has a universal screening programme for newborns (Sickle Cell Society, 2018). Although some in the current study were diagnosed as teenagers or adults, the majority of those with SCD will be diagnosed as children and their first interactions with doctors will be as children, with their parents or guardian taking responsibility in consultations, for medical decision making, and for their medical care, including the taking of medicine over time.

Some participants spoke directly about how their transition from child to adult services was not handled well, directly impacting on their ability to adjust to the shift in roles and responsibilities as they became self-sufficient adults. Transition has been described as “the purposeful, planned movement of adolescents and young adults from child-centred to adult-oriented health care systems.” (Inusa et al., 2020, pe329). Transition has been identified as a period of time when those with SCD can be particularly vulnerable, with data from both England and the USA identifying higher risk in terms of hospital admissions and mortality around the time of transition (Quinn et al., 2010; Renedo et al., 2019). Accordingly, guidelines for the care of those with SCD recommend that specialist teams should have a policy and dedicated team for transition, which should include a named transition-lead (Sickle Cell Society, 2018).

A qualitative study conducted with young people across two cities in England (Renedo et al., 2020) examined the experience of those with SCD of transitioning from paediatric to adult services. One of the key findings relevant to the current study was that young people also had relational difficulties when transitioning from paediatric to adult services, although not necessarily in the manner identified in the current findings. This study reported that participants experienced a lack of involvement in decisions about their care because staff did not recognise their expertise.

Whereas staff not acknowledging patients' own self-knowledge was raised as an issue in the current study with regards to decision making and adherence to hydroxycarbamide, other relational difficulties linked to the process of transition were also found. For example, Ivy deferred to her doctors' decision regarding hydroxycarbamide, leading her to continue to take the medication even when she felt it was no longer working for her, whereas Aidan, in moving from child to adult services, felt disappointment due to no longer receiving the same level of care and consideration he did when he was a child.

Perhaps crucially, both Ivy and Aidan changed their behaviour towards becoming more self-sufficient, meaning that they sought to understand and manage their SCD independently, rather than rely on the input of the health professionals around them, as a result of these experiences. Previous research has found similar results. The qualitative research by Renedo & colleagues (2020) cited above, also found that negative health care experiences around the time of transition could create uncertainty about the quality of care in hospital, which could have a negative impact on future willingness to present to hospital (Renedo et al., 2020). Previous qualitative research with people with SCD in the USA has found that those with SCD reported avoiding attending hospital when in pain due to previous negative experiences (Jenerette et al., 2014).

With regards to the assumed roles and responsibilities that participants discussed in the present study, it is possible that cultural factors may also be relevant here. As described in the previous chapter, some participants seemed to speak of a moral aspect to following doctors’ advice and deference to doctors’ authority.

Several participants identified as African, and others who identified as Black British spoke in accents that I identified as being African in origin. As was mentioned in Chapter 1, previous research has found those from some African backgrounds preferentially defer to the wisdom and judgement of their doctors in decision making (Agyemang et al., 2021; Norman, 2015). Whilst it is possible that such deference might positively influence the uptake and adherence to medication, it can also represent a philosophical challenge to the collaborative principles of shared decision making espoused in the UK (National Institute for Health and Care Excellence, 2021b)

At other times, participants seemed to relate to their doctors based on an unconscious template, as would be expected under the premise that attachment systems have been activated. Although the present study did not assess participants’ attachment styles, it did appear that participants experienced the relationship with their doctors in different ways that were meaningful and potentially impactful in terms of initial decisions to take hydroxycarbamide and subsequent adherence. For several of the participants, it appeared that their relationship with their doctor was unproblematic; it is plausible that in these instances the relationship was experienced as a secure base that supported initial decision making and subsequent adherence. For others, this was not the case, resulting in difficulties in making choices, taking in information and disclosing information that had a real impact on their medication behaviours. These are discussed in further detail in Section 4.2.4, below.

Correlations between the attachment characteristics of patients and the way they present themselves in the healthcare system have been found in previous research (Hunter & Maunder, 2015). For example, those with secure attachment have been found to communicate openly with healthcare providers and be more responsive to treatment that is provided, whereas those with dismissive attachment style may avoid caregivers when symptomatic, devalue the input of others and be less likely to comply with treatments that have been recommended.

One important route for attachment security to impact on interactions where hydroxycarbamide is discussed is by increasing the likelihood that a source of information, such as a doctor or other healthcare professional, is trusted, when the information delivered is reasonably credible (Fonagy & Allison, 2014). Importantly, as well as trusting information from others, secure attachments also generate confidence in and empowers one’s own judgement (Fonagy & Allison, 2014). This will be discussed in further detail in the next section.

### *4.2.3 Discussion of Theme 3: Maintaining independence*

This theme explored how many participants had developed deep knowledge of their own bodies and robust personal models of understanding of how SCD impacted them personally. Logically, this proposition makes sense. All participants in this study were adults and all but one had been diagnosed in childhood or adolescence, meaning that they would have had significant lived experience of SCD, its impact on their body as well as how to manage it both personally and from a medical treatment standpoint. From a relational perspective when considering medical encounters where hydroxycarbamide was discussed, similar to the sense of vulnerability described above, one important function of this self-knowledge was as an aspect of the person with SCD that it was incumbent on the doctor to understand and acknowledge.

With regards to having a well-developed understanding of their own SCD, a similar finding was reported in the study by Renedo and colleagues (2020), described above. Participants in their study described themselves as knowledgeable about their body, their experience of pain and of how medications and other therapies impact upon their individual bodies.

The common-sense model of illness self-regulation (Leventhal et al., 2016) is a theory which describes the process by which people with chronic conditions such as SCD form beliefs about their illness, grounded in experience. Behaviours, such as choosing to take a medicine or to adhere to a medicine flow “logically” from these personal, common-sense understandings. Perhaps of particular relevance to the current findings, as these illness representations reflect “common sense” models of an illness, they do not necessarily need to match with the perspective of evidence based or expert models, and the response of patients will also make sense from the perspective of the individual’s “common sense”. (Leventhal et al., 2016). These common sense models may also prioritise wanting to avoid the potential side effects associated with hydroxycarbamide, a concern that was present in the current findings, and has been found in previous research (Brandow & Panepinto, 2010; Brawley et al., 2008). Thus, what is considered to be best from the perspective of the healthcare professional, may not match what the patient considers to be best for them. This has relevance both for shared decision-making and subsequent adherence. Shared decision-making, as exemplified in many of the interactions participants had with their doctors, tends to elevate evidence-based, medical knowledge over other types of information. However, as theorised using the common sense model, patients often value their own experiential knowledge over that of experts when making choices regarding treatment (Diefenbach & Fleszar, 2018).

Whereas virtually all participants seemed to describe an understanding of their own SCD, how this played out in interactions where hydroxycarbamide was suggested or monitored appeared complex and dynamic and perhaps influenced by relational variables. For example, as described above, Aidan was not sure whether hydroxycarbamide was appropriate for him and was leaning towards not taking it, Eileen was not sure whether hydroxycarbamide was for her, but having wrestled with her doctor regarding whether to take it, had given it a go, and Ivy had accepted her doctor's recommendation, felt it was not working for her, but persisted in taking it. Thus, for these participants at least, the link between their common-sense model of SCD and behaviour did not appear to be linear, rather, appeared influenced by relational variables.

Previous research in those with SCD in the USA have found personal models of illness in those with SCD, in terms of current perceptions of health status, to be associated with the decision to take hydroxycarbamide. The qualitative study published by Jabour and colleagues (2019) that examined the decision-making process in those with SCD with regards to taking hydroxycarbamide found that participants' current health status impacted on their decision to take hydroxycarbamide, with those more likely to take it if it offered the potential of improving their health. Similarly, a qualitative study conducted by Alberts and colleagues (2020) found that those who perceived low SCD severity reported a lack of need to take hydroxycarbamide.

Returning again to theories of mentalisation, it has been suggested that those with insecure attachment profiles are more likely to be threatened by information challenging their existing knowledge structures, such as their common sense models of illness, due to their sense of self being vulnerable, particularly if threatened by being emotionally overwhelmed (Mikulincer, 1997). If such overwhelm is anticipated, those with insecure attachment may instead opt to maintain knowledge stability, which has the effect of serving to temporarily down-regulate arousal. Previous research has found that those with insecure attachment are less likely to accept revisions to their knowledge when faced with information that contradicts or challenges their previous assumptions (Green et al., 2017; Mikulincer & Arad, 1999).

Whilst superficially it seems like there might be a contradiction here, i.e. in both having trust in one's self and in others, theorising on mentalisation and attachment has found that those with secure attachments from childhood are able to use flexible strategies where the likelihood of trust in a reasonably credible source of communication is more likely, but additionally one's confidence in one's own experience and belief is also increased (Fonagy & Allison, 2014). Thus, those who are securely attached can have trust both in their doctor and in their own self-knowledge and act accordingly, whereas for others, new knowledge can be rejected in favour of prioritising self-knowledge and remaining self-sufficient.

#### *4.2.4 Discussion of Theme 4: The adequacy of the response*

In contrast to the first three themes, which were primarily concerned with variables within those with SCD, this final theme described participants experiences of their doctors' responses to them in their interactions where hydroxycarbamide was discussed. Feeling held in mind over time and having anxieties contained, feeling a sense that their doctor was not attuned to their needs, and that their doctor engaged in reassuring action all seemed to directly address the research question and be relevant factors in initial decision making around taking hydroxycarbamide and subsequent adherence.

Feeling *held in mind* and *containment* are concepts more commonly used in relation to psychoanalytic therapy but are relevant here and seem to speak to the data more readily than attachment theory, although within the spirit of critical realism, there are invariably overlaps between concepts that deal with the psychological legacy of experiences of parenting. The concept of *feeling held* is commonly attributed to Winnicott (1965) to describe a feeling state of being held in the arms of a primary caregiver. This concept is typically discussed in relation to the analytic setting; the *facilitating* or *holding environment,* with its qualities of stability, regularity and continuity, is considered the basic condition for analytic therapy to support the development of the client. Thus, conceptually similar to  the secure base concept in attachment theory in its concept of the experience of a relationship that provides a sense of security that allows one to surmount obstacles and self-manage through adversity over time (Marrone, 2014).

In the present study, many participants seemed to glean comfort from having had the same doctor over time, or perhaps more pertinently, seemed to feel anxious or disconnected from their healthcare when seeing a different doctor each time they went to the hospital. This finding is broadly in line with previous research with medical populations. A systematic review synthesising qualitative studies that reported patient perspectives on continuity of care reported that one common finding across studies was that patients’ felt more confident in their doctor and their doctor’s advice when care was continuous (Nowak et al., 2021).

Again, trust is a relevant aspect to consider. Whereas the discussion of trust in Section 4.2.3, above, centred more on trust in information received, a broader conceptualisation of *relational* trust is also relevant here. Research has shown that doctor-patient relationships where trust is present contribute to better care experiences, the enhancement of patients' involvement in medical decision making and can also alleviate patients' anxiety and distress (Dean & Street Jr, 2014; Shepherd et al., 2008; Thorne et al., 2005). With regards to those with SCD, research from the USA has found that those with SCD often have little trust in healthcare professionals, and this has been associated with poorer adherence to treatment (Haywood Jr et al., 2010; Stanton et al., 2010).

The concept of *containment*, again more commonly discussed in relation to psychoanalytic therapy, is drawn from the work of Bion (1962) where he described the theory of the container and contained; a process whereby a primary caregiver takes on their child's projections, metabolises them, and then returns them in a form that can be more easily tolerated by the child.

A similar process appeared to be in play with some of the participants in the current study, particularly with regard to the experience of side effects. To use the example of Vanessa, who struggled when initially taking hydroxycarbamide due to the unpleasantness of side effects. In response, their doctor took their experience and concerns seriously, ran some tests, and fed their experience back to them as one that was not cause for concern. Thus, adequate containment of Vanessa's concerns appeared linked to their resolve to continue adhering to hydroxycarbamide over time.

Thus, and as described in the results, the actions of doctors, and how doctors' actions were perceived by participants seemed crucial. Some relevant literature examining the content of communication by doctors was found, however, a systematic review of prospective cohort studies looked at associations between components of communication carried out by doctors in consultations with patients presenting with pain and discomfort (Pincus et al., 2013). The authors compared aspects of *affective communication* aiming to reduce worry, create rapport and reassure patients, which one might consider likely to induce feelings of containment within patients, with cognitive reassurance, which aims to change perceptions and beliefs through education (Pincus et al., 2013).

Perhaps contrary to the current findings, which seem to suggest that affective communication would be beneficial to patients, the authors looked at a range of outcomes including adherence and found that cognitive reassurance was associated with improved outcomes immediately following consultation and at subsequent follow-up points, whereas  affective reassurance was associated "*at best only with improved satisfaction and at worst with poorer outcomes*" (Pincus et al., 2013) (p2413).

Closer examination of included articles suggests a muddier picture however. Whereas the "affective communication" aspects contained behaviours and aspects of communication such as "Being comforting and caring" and "Rapport building, socializing, facilitation, and engagement", the cognitive aspects included elements including "Discussing options, working to adjust treatment, answering clearly, explaining, checking understanding, demonstrating competency" and "Explanation and diagnosis, treatment recommendations, advice on returning to normal activity" (Pincus et al., 2013, p2412). Based on the current findings, it is possible that each of these cognitive aspects of communication also bring affective benefits, such as sense of containment.

As described in the previous chapter, at times participants seemed frustrated, anxious or disappointed when they perceived that their doctor did not share their understanding of their own illness. At times their negative feelings about the situation seemed linked to not having their individuality, as expressed through their deep knowledge about their own illness, recognised. At other times, participants seemed to feel that their core vulnerability, their real issues were not being responded to.

Returning again to the NICE definition of shared decision making (National Institute for Health and Care Excellence, 2012b, p32) which describes: *"a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care… It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values".* It appears that for these clients, this threshold was not met for some participants. For Aidan and Eileen in particular, hydroxycarbamide was being recommended to them not based on their own preferences, beliefs or values. As a result, at the times the interviews were conducted, Aidan was leaning against taking hydroxycarbamide, whereas Eileen had, in her words, "relented", albeit without much enthusiasm.

'Common factors' approaches to psychotherapy posit the idea that what different psychotherapies have in common, and what is fundamental to their effectiveness, is that they create within the client or patient a sense of being understood, despite differing in the theories and models of understanding they posit (Fonagy & Allison, 2014). For Aidan and Eileen, a sense of being understood was absent, and this appeared to impact directly on their decision to take hydroxycarbamide.

## 4.3 Theoretical and clinical implications

This research provides insight into the experiences of people with SCD in medical encounters where hydroxycarbamide has been initially discussed and monitored over time. It shows how both intra-psychic relational variables and inter-psychic relational processes appear to be present and pertinent in these encounters. The current research provides several theoretical and clinical implications, and these are examined further in this section.

Attachment theory provided a useful framework for understanding many of the findings presented here, particularly those intra-psychic variables such as consideration of variability in individual attachment patterns and how these might be linked to, e.g. trusting information from doctors when hydroxycarbamide was being introduced.

Although in the introduction, this research critiqued cognitive and behaviourally-oriented interventions that focussed on targeting rational, intra-psychic variables within the individual such as beliefs, attitudes or intentions (Michie, Van Stralen & West, 2011), with hindsight it is possible that attachment theory, with its focus on childhood experiences and internal working models of relationships represents a relational intra-psychic model, thus potentially reinforcing the notion that low rates of uptake or non-adherence to hydroxycarbamide be located within the person with SCD.

Further, and in line with the pluralistic ethos of this study, some aspects of the current findings seemed better accounted for by other theories, which encompassed a more dynamic, inter-personal stance, such as those described above from psychoanalytic theory. A previous systematic review and meta-analysis of studies predicting adherence to medication reported that adherence was predicted by multiple models and extended models. The authors concluded that “no single theory should be used to inform the development of adherence enhancing interventions” (Holmes et al., 2014, p874).

One potential implication of the current research is that potential future interventions, rather than focussing solely on intra-psychic variables within the person with SCD, nor solely on what the doctor is delivering in terms of intervention content, but instead should *also* pay attention to what is going on *between* patient and practitioner.

With this in mind, it may have been prudent with hindsight for the current study to select a theory to focus on how those with SCD *feel* about their health care providers *in the moment* when they are speaking with their doctors, and when crucial information regarding medication is being exchanged, as it seems, based on the current findings that this may be more important than what their provider does *per se*. Ivy’s experience of feeling uncontained and reporting “*when it came to taking in information I found I didn't take it in like really well”* (Ivy, 114-115) is of particular interest here.

In psychotherapy, it is commonly assumed that effective therapeutic work can only be possible if the client feels safe and secure (Geller & Porges, 2014). `Polyvagal theory explains the response of our nervous system to the external environment. According to the theory, effective social communication, such as exchanging information about the risks and benefits of taking hydroxycarbamide, or on how to adhere to hydroxycarbamide over time, can only occur when we are in a state when we experience safety, because it is only then that our neurobiological defence strategies are inhibited (Geller & Porges, 2014). Further, perceptions of safety and positive regard activate the parasympathetic nervous system (PNS), which has the effect of encouraging connection and engagement, both key ingredients of an effective therapeutic relationship (Dana, 2018).

An important corollary of this is that it requires the person delivering the intervention in the dyad to be fully present and try to promote client safety to ensure that the client or patient’s social engagement system is potentiated, and their involuntary defensive subsystems are down-regulated (Geller & Porges, 2014). The interventionists ability to induce feelings of safety within the patient is dependent on their own ability to self-regulate and to hold genuine positive regard of the patient (Dana, 2018). The word genuine here is crucial; polyvagal theory holds that cues for safety and threat are perceived largely subliminally via a variety of subtle manifestations and perceptions that cannot be faked or simulated (Geller & Porges, 2014). Thus polyvagal theory is in alignment with the core components of person-centred theory: genuineness, empathy, and unconditional positive regard (Rogers, 1957).

Thus, from this perspective, decision-making and adherence, rather than behaviours performed by an individual in isolation, can therefore also reasonably be conceived as the *outcome* of the interaction between patient and healthcare practitioner. One can assume therefore that, in a manner analogous to the quality of the therapeutic relationship determining outcome in research on treatment for psychological problems as outlined above, the experience of the encounter between intervention provider, most likely a doctor or other health care professional and a patient with SCD could be important when considering whether one opts to use and adheres to a medication such as hydroxycarbamide.

There is evidence that suggests that, despite patient preference for shared decision making and how it is emphasised in determining decision making, the doctor-patient relationship may play an equally important and independent role in the outcome of the decision-making process (Schoenthaler et al., 2018). The word equally here is important when considering the clinical implications of this result. It is important to note that the implication of this study is not to suggest that relational variables and attachment are of sole importance when considering how best to promote uptake of and adherence to hydroxycarbamide in those with SCD.

In contrast to Rogerian, person-centred principles, the alternative position, i.e. that the relationship is sufficent for behaviour change is also likely incorrect. For example, a systematic review of app-based interventions designed to support adherence to medication found that those using mobile apps to facilitate adherence were more likely to self-report adherence than those in control groups (Konstantinou et al., 2020). Thus, meaningful behaviour change can be achieved in the absence of any therapeutic relationship.

Further, it has been argued that the particular techniques used by an interventionist may be closely linked to the quality of the therapeutic relationship as perceived by the person receiving the intervention. A study conducted by Bedi and colleagues (2005), examining factors leading to the formation of a therapeutic alliance reported that technical interventions, such as being asked to do homework, were the incidents cited most often. Thus, when trying to encourage the uptake of hydroxycarbamide by those with SCD, or promote adherence, it seems likely that all aspects of an encounter from the intra-psychic characteristics of the person with SCD, to the intervention components delivered to promote behaviour, to the practitioner’s delivery of these components, their response to the patient and the shared relationship contribute both individually and in combination to the outcome.

With regards to specific implications for counselling psychologists, firstly, it seems clear that the discipline, with its pluralistic ethos, meaning it can work across theories, and its deep understanding of the therapeutic relationship as a key driver of change, is well placed to provide training to doctors or other front line medical staff who recommend medication or who monitor or promote adherence to medication in those with SCD or other chronic conditions. This training should emphasise the importance of the *being with* aspects of encounters with patients in addition to the active ingredients of any interventions. Through supervision and consultation, counselling psychologists could also work with other medical professionals to foster a more nuanced, relational approach to shared-decision making interventions that help medical professionals to distinguish both autonomy-undermining and autonomy-promoting social influences (Dove et al., 2017).

In terms of direct clinical work, as well as assisting those with SCD or other chronic conditions who are experiencing difficulties adhering to their medication, counselling psychologists working within multi-disciplinary teams could also help other clinical staff, crucially from a pluralistic theoretical perspective, to support patients in achieving these outcomes. More broadly, counselling psychologists could work within teams to further the psychological skills of staff who provide direct care to patients. The need for such work has been highlighted by a report written by the Psychological Professions Network (2020) who noted a current lack of psychological training in physical healthcare organisations.

As well as potentially improving direct work with patients, input from counselling psychologists could also benefit the broader culture within the multi-disciplinary team, enabling them to become more psychologically minded which could also improve working relationships between team members for example by improving communication and collaboration, and creating a supportive environment where each team member’s contribution is appreciated by promoting key counselling psychology, for example of empowerment and valuing subjectivity (Cooper, 2009). Good relationships between team members have been found in previous studies to reduce the likelihood of burnout (Gisick et al., 2025; Lu et al., 2023).

One important conclusion that counselling psychologists can take from this study is that working with those with SCD in healthcare settings is extremely complex as it will demand balancing ‘medical model’ ideas about what is best for each patient, for example that hydroxycarbamide is indicated, alongside “common sense” models and, for example, concerns about side effects or the appropriateness of treatment. Cultural and historical considerations are also relevant, for example considering differences in the need for autonomy, and the past stigmatisation of those with SCD and how this might impact upon both the therapeutic relationship and relationship with the healthcare system.

Shillito-Clarke (2010) has written about how counselling psychologists, at times, can struggle with the nuanced distinctions highlighted in these findings, for example between trusting the client or patient to know what is best for his or her self, and their personal desire to take control to help the client. Thus, it is held that the ethical imperative for counselling psychologists is to be self-aware and to reflect on these issues. BPS Practice guidelines (British Psychological Society, 2017) emphasise the role of supervision as a key aspect of reflective practice in allowing for the provision of a space where a supervisee can reflect in an uncensored manner and grapple with complex, at times contradictory, and difficult concepts such as those described here. In an ideal world, a supervisor would provide a ‘secure base’ to facilitate in the supervisee the capacity to regulate their own emotions and explore themselves, their clients and their practice (Marrone, 2014).

BPS Practice guidelines (British Psychological Society, 2017) also emphasise the importance of Continuous Professional Development (CPD) and this research also suggests some potentially important gaps in knowledge for counselling psychologists working in healthcare settings with those with SCD, for example information on shared decision making in health settings, or medical aspects of SCD, which are likely not routinely taught as part of training in counselling psychology.

## 4.4. Quality and limitations

As was introduced in Chapter 2, the evaluative criteria proposed by Yardley (2000) were followed in order to ensure the quality and credibility of the current research

### *4.4.1 Sensitivity to context*

In Chapter 2, the epistemology and philosophical approach for the current study was outlined along with a full description of how the approach aligned with the chosen research method for answering the research question. The rationale for the study was also described in terms of practical considerations, previous literature and relevant theory. Further, the research topic was chosen based on the researcher’s academic background in health-related behaviour change experience, training in counselling psychology, and experience working with people with SCD.

### *4.4.2 Commitment and rigour*

Following on from the above, the research topic was chosen as one that was of particular interest to the researcher, having worked for several years in health behaviour change researcher, including having produced research in self-management in those with chronic illness and medication adherence, before training as a practitioner grounded in relational psychotherapy. Thus, the study meets the criteria for commitment through prolonged engagement with the topic, as well as through the researcher’s competence in the application of the chosen methods (Yardley, 2000).

With regards to rigour, which refers to the completeness of data collection and analysis (Yardley, 2000), Braun & Clarke (2022) recommend consideration of concepts such as *information power* rather than *sample size* or *data saturation*, which they argue are more grounded in positivist-empiricist than in “big Q” qualitative research.

Consideration of information power “invites the researcher to reflect on the information richness of their dataset and how that meshes with the aims and requirements of the study” (Braun & Clarke, 2022) (p28). As mentioned in Chapter 1, to my knowledge, no prior study has examined the experiences of those with SCD when interacting with healthcare professionals with regards to the initial decision to take hydroxycarbamide, nor with regards to adherence over time. The results of the current study provided insight into these relational experiences, that could be understood in term of theory and provided findings that aligned with previous research from the those with SCD in the UK.

Finally, although attachment theory was chosen as the theoretical framework for the research, it was not adhered to unquestioningly and uncritically. As was mentioned above, other theories were used to account for some aspects of the current findings. Braun & Clarke (2022) caution against uncritically using existing concepts and theory when conducting RTA, as working solely deductively within the framework of existing theory can result in an impoverished analysis. This was not the case in the current study as concepts from other theories were incorporated into the analysis to provide a more accurate understanding of participants' experiences.

### *4.4.3 Transparency and coherence*

The study aimed for a process that was transparent and emphasised coherence with regards to the alignment of the chosen research questions and methodology (Yardley, 2000). Further, as described in Chapters 2 and 3, clear processes were followed and evidenced throughout to produce a coherent set of findings that could be understood in relation to extant theory and literature. Examples were provided to evidence the process of coding (see Appendix H), codes produced and the development of themes (see Appendices I and J). In presenting the findings, the research aimed to appropriately outline the deductive and inductive analysis used and evidence each theme and subtheme through selection of illustrative quotes.

### *4.4.4 Impact and importance*

The current research has aimed to meet this criterion by describing the importance of the work by evidencing how no prior study in the UK has examined the experiences of those with SCD when interacting with healthcare professionals with regards to the initial decision to take hydroxycarbamide, nor with regards to adherence over time. Further, theoretical and clinical implications are discussed along with ideas for future research, each of which have relevance both for the field of counselling psychology and the broader academic community.

### *4.4.5 Limitations*

Although the research aimed to adhere to Yardley's (2000) criteria for quality qualitative research and Braun and Clarke's (2022) 15-point list of criteria for RTA, this research has some limitations.

As was mentioned in Chapter 2, the original plan for this research was to focus solely on adherence to hydroxycarbamide, and particularly on how the relationship between the person with SCD and their doctor was experienced in the initial difficult period of starting to take the drug. Broadening out the scope, whilst arguably ensuring that it was possible to recruit enough participants and complete the study, perhaps did so at the expense of focus within interviews, and homogeneity of experiences between participants. Given the diversity of experiences of participants with regards to hydroxycarbamide, it is possible that this original study would have provided greater information power as there would have been greater homogeneity of experiences within the study. Against this, and as mentioned in the previous section, it was possible for the current study to produce a coherent set of results that could adequately answer the research question.

There was also heterogeneity in the extent to which participants engaged with me and the interview questions, as exemplified by the interviews lasting between the broad range of 26 and 69 minutes. One potential explanation for this is the mode of recruitment, which was not via the NHS. It is possible that, particularly in the case of those who have a good relationship with their healthcare providers, that recruiting through the NHS might have enabled me to be seen as part of the secure base of their trusted medical staff, facilitating greater comfort and exploration of the issues raised. Of course, the converse is also true, and my sense is that some of those participants who spoke for the greatest duration were those who had less good experiences. Thus, may have attached to me more readily, and felt more able to explore and be critical of their healthcare providers due to my not being connected to this setting.

*Clearly an important aspect to consider with regards to sensitivity to context is my status, as described in Chapter 2, as an outsider researcher, in a more privileged position working with a potentially marginalised group. In my analysis of these data, I have taken what the participants told me at 'face value', as direct reflections of their thoughts and feelings (Willig, 2013). However, context is important, and given the interviews were concerned with the relational context within which medical encounters took place, it would be naïve of me to ignore the context within which the current interviews took place.*

*Braun & Clarke (2022) discuss how one is perceived as an interviewer, and what we might represent in connection to longstanding challenges from marginalised or exploited communities can impact on what participants choose to conceal or reveal. Whilst I would like to assume that my race did not impact upon the interviews, I cannot assume that this was the case. One participant expressed surprise after her interview was completed that their interviewer was white and enquired as to how I became interested in the topic. Furthermore, aside from Eileen who mentioned in passing about how in previous times she would have been treated "like a junkie" (Eileen, 608) if she asked for pain medication, no participant mentioned experiences of racism or discrimination, despite the findings of the No One's Listening Report (All Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021) described in Chapter 1. Whilst it is possible that this accurately represents their experience, I am* *cognisant of the possibility that they may not have felt comfortable disclosing experiences of racism to me.*

*I also noticed that some participants expressed a reluctance to criticise their doctors, even when they had not had good experiences with them. Whilst this can be understood from the relational perspective, as was described in the previous chapter, I feel that it can also be considered contextually. I acknowledge that it is also possible, given that I explained that I had worked in haematology departments in the NHS as part of my training, that I may have been seen as “part of the system” and so participants may have been reluctant to be critical, lest it jeopardise their care.*

*Willig (2013) also discusses how the interview may serve as a prompt for an interviewee to begin to think about aspects of their experience in new or different ways. I also noted that several participants said to me that they had never thought about their relationship with their doctor before. Further, Aidan openly discussed with me about how our conversation was prompting him to re-evaluate his experiences of discussing hydroxycarbamide with his doctor. Thus, whilst links with extant theory and research literature provide some evidence of external validity for these findings, the impact of the methodology and the researcher on these findings is also acknowledged.*

Finally, although attachment theory providing the starting point for the theoretical understanding of the current study, attachment styles were not formally evaluated. This could have been achieved using one of the self-report measures developed to assess attachment styles that have been found to have some evidence of validity and reliability, for example the Attachment Style Questionnaire Short Form (ASQ-SF) or the Treatment Inventory-Attachment Style Scales (PTI-ASS) (Justo-

Núñez et al., 2022). Participants' attachment styles could then have been considered alongside a qualitative analysis of their experiences of medical encounters in a mixed methods study, which are considered to have the potential to provide a more complete picture of the area of research and allow the exploration of complex phenomena from different perspectives (Bryman, 2006). Thus, it could be argued that a mixed methods study might be more aligned with the pluralistic nature of this research.

Against this, it could also be argued that formal assessment of attachment styles might also have constrained the current analysis, which ultimately moved beyond attachment theory to understand and contextualise the findings. Requiring the completion of formal measures of attachment would also have further increased the burden placed on participants. Finally, it could also be argued that a quantitative element that sought to incorporate statistical analysis, for example to consider associations between attachment style and measures of opting to use hydroxycarbamide versus not, and of adherence to hydroxycarbamide, would have been difficult to accomplish due to the increased number of participants that would need to be recruited. As an example, a study examining attachment style and hypertension medication adherence which reported adequate power to test these associations recruited 237 participants for a continuous outcome of adherence (Hooper et al., 2016). The sample size needed to look for variability by attachment style in a binary variable of chose versus did not choose hydroxycarbamide would be significantly more large (Campbell et al., 1995).

## 4.5 Future Research

Although the current study yielded coherent and impactful findings, future studies may want to examine the experiences of encounters concerning decision making and adherence separately, to corroborate or disconfirm the current findings, but also to allow the production of potentially more rich and nuanced data that could come from a research process with a tighter focus.

Should similar findings be produced, prospective, observational studies could then be planned to examine whether relevant variables, for example containment or feeling held are associated with subsequent decision making or adherence to hydroxycarbamide. Further to this, experimental studies could then be planned to examine, for example, whether training doctors to pay attention to patients and make relational adjustments, or involving counselling psychologists in the relationship, could improve information intake, retention and ultimately uptake and adherence.

Mindful of excess focus on the patient and locating the source of problems therein, future research might also want to consider attachment or other relational intra-psychic variables within doctors. Few studies on this topic have been conducted, but there is some evidence in medical students to show that there is some effect, for example research has found that attachment styles are related to levels of empathy (Ardenghi et al., 2020) as well as both communication and clinical skills (Fletcher et al., 2016).

Future research might also want to examine the potential impact of systemic and cultural issues on medical encounters. For example, although none of the participants in the present study mentioned the ethnicity of their doctors or other healthcare providers, however there is significant scope for the ethnicity of the doctor and patient in the dyad to influence power dynamics within medical encounters. For example, it is possible that shared ethnicity between doctor and patient to lead to improved communication, trust, and understanding, through alignment in language, health beliefs, and perhaps most relevant to the current study, cultural norms particularly with regards to communication styles and need for autonomy (Ryan et al., 2008). Previous research has found ethnic minority patients to prefer to receive care from physicians of their own ethnicity (Saha et al., 2003). Similar dynamics have been hypothesised to influence the quality and outcomes of doctor-patient relationships with regards to gender (Thornton et al., 2017).

Conversely, when there is a difference in ethnicity within the doctor-patient dyad, a misalignment in these same variables can occur, potentially leading to an unhelpful dynamic whereby the patient feels less able to actively participate in their healthcare. Further, there is potential for systemic issues such as racial discrimination or stereotypes to further exacerbate these power imbalances (Howard et al., 2001; Ryan et al., 2008).

The No One's Listening Report (All Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021) reported a frequent, racist assumption within the NHS that those with SCD were drug-seekers, and not in genuine pain when presenting at hospital. Previous research has indicated that those with SCD often perceive that their healthcare providers have negative attitudes towards them, which can often result in these patients feeling stigmatised and mistrusted (Miller et al., 2024; Wakefield et al., 2017).

The potential impact of gender is another factor that should be explored in future studies. There are some similarities with how those with SCD have been treated by the medical establishment and how women have been treated historically by the conventional medical model as “hysterical” or emotionally unstable.

Historically, women's health issues were often dismissed as psychological or emotional, leading to a pattern where their symptoms were not taken as seriously as those of male patients. (Paulon, 2022). Previous research found evidence that women presenting in healthcare settings with pain due to endometriosis have experienced dismissal and trivialisation due to the gendered nature of the condition and that this led to perceptions of low confidence and control (Moradi et al., 2014). One can only assume that for women presenting with SCD in healthcare settings, multiplicative, intersectional impacts are possible.

The relative ages of the doctor and patient may also have an impact on a patient’s experience of the medical encounter. One previous study found that more patients prefer a doctor in their 50s than their 60s, with the authors speculating that the younger age group might be perceived as being at the peak of their career (Thornton et al., 2017), and may therefore provide a more containing relational experience. Other research has also found that doctors performed behaved in a manner deemed to be more patient-centred with patients over the age of 65, which in turn led to older patients being more satisfied with their care (Peck, 2011).

To my knowledge, the extent to which concordance or differences in ethnicity, gender or age impact upon the formation of secure attachments in doctor-patient dyads has not been examined. However, previous research has found that gender concordance was associated with greater trust (Bonds et al., 2004) and that racial concordance was associated with higher levels of perceived communication and respect (LaVeist et al., 2003; Saha et al., 2003). It is possible, therefore, that concordance between patient and doctor along these characteristics facilitates the perception of the healthcare provider as a “secure base”, however this would need to be explicitly examined in any future research, as would the extent to which such differences can be transcended and how this might be achieved.

Finally, future studies might also want to separately consider the experiences of those with SCD who were diagnosed in childhood compared with those diagnosed in adulthood, and those who were recommended to use hydroxycarbamide in childhood compared to in adulthood as the current findings suggest that there may be differences between these groups. Previous research into families containing a child with a chronic illness such as SCD (Suris et al., 2004) suggests changes in the family dynamic, for example becoming overprotective of the child, that could conceivably impact upon how this child subsequently relates to others, and that this might be different for someone who was not ill during their childhood and diagnosed in adulthood. This difference was an unforeseen consequence of the arguably over-inclusive inclusion criteria of the current study, and any future research might want to constrain their inclusion and exclusion criteria accordingly to recruit more homogenous samples.

## 4.6 Chapter Summary

This chapter served to conclude this research project through discussion of the findings and situating them within the extant research literature. Furthermore, it outlined the theoretical and clinical implications of the study, along with a discussion of the study’s limitations, and the researcher’s final reflections.

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# APPENDICES

## Appendix A: Advertisement used to recruit participants

# PARTICIPANTS REQUIRED FOR RESEARCH PROJECT

### WHAT IS THE PURPOSE OF THE RESEARCH STUDY?

We are interested in learning more about the experiences of those with sickle cell disease when speaking with medical professionals about hydroxycarbamide. We hope that this research will provide greater understanding on why those with sickle cell disease decide to take or not take this medication and whether anything can be done to improve these experiences.

### WHAT WOULD THE STUDY INVOLVE?

You will be asked to participate in an interview with Máirtín McDermott, which will take approximately 60 minutes. The interview will be conducted online using Microsoft Teams. You will be asked questions about your experiences of being recommended to take hydroxycarbamide, who made the recommendation, your thoughts about that person and whether you subsequently decided to take hydroxycarbamide or not. All those who take part will receive a £40 one4all voucher.

### 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 been diagnosed with sickle cell disease.
You have been recommended to take hydroxycarbamide at any time.

### WHAT NEXT?

If you are interested in taking part or if you would like more information, please contact:
Máirtín McDermott
Counselling Psychologist in Training
University of East London
Email: u2069674@uel.ac.uk

Recruitment poster V2, 20/02/23
Study title: A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide.

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## Appendix B: MS Teams Interview Guide

### START RECORDING

Hello (participant name), thank you for agreeing to talk with us today. I think it would be useful to begin by giving you some information about how this interview will proceed.

In total, I'd expect this interview to last between 45 minutes and an hour.

Have you had the chance to read through the information sheet? Have you got any questions?

Some information about you:
The purpose of this is to give us a flavour of who we spoke to for this study and to help contextualise some of your responses. It's also a useful way to start the interview with some easy questions. Obviously, as with all information you give us this will be anonymised, held in the strictest confidence and it wont be possible to identify you from any report of this study.

| | |
|---|---|
| **Age** | |
| **Gender** | |
| **Ethnicity** | |
| **Employment status** | |
| **Full time?** | |
| **Live in the UK?** | |
| **Diagnosed with SCD?** | |
| **When diagnosed (years)** | |
| **Current treatment?** | |
| **Which hospital?** | |
| **Postcode** | |
| **Currently taking hydroxycarbamide?** | |
| **Ever taken hydroxycarbamide?** | |

If taking hydroxycarbamide:
    How long have you been taking it?

What has your experience of taking hydroxycarbamide been?
        Any perceived benefits?
        Any side effects?

What can you tell me about your experience of being recommended to take hydroxycarbamide?
    Who recommended that you take it?
    How do you feel about that person?
    How would you describe your relationship with this person?

What was your experience of taking the decision to take hydroxycarbamide?

Why did you decide to take it?

How often do you have to take it?

Do you take it as was recommended?
    Why/ Why not?

Do your healthcare providers check adherence?
        What has your experience of this been?

**If not taking hydroxycarbamide:**

What can you tell me about your experience of being recommended to take hydroxycarbamide?
    Who recommended that you take it?
    How do you feel about that person?
    How would you describe your relationship with this person?

What was your experience of taking the decision to take hydroxycarbamide?
    Why did you decide not to take it?

*Probing questions*
Could you tell me more about that?
What is that like for you?
When, why, how?
How do you feel about this?
Have these feelings changed over time?
Why do you think this is?
What do you do about this?
What did you make of that?
What did you mean about that?

## Appendix C: Ethics Review Approval Letters

**School of Psychology** University of East London **Ethics Committee**

# NOTICE OF ETHICS REVIEW DECISION LETTER

**For research involving human participants**

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**Reviewer:** Please complete sections in blue | **Student:** Please complete/read sections in orange

## Details

| | |
|---|---|
| **Reviewer:** | **Fiorentina Sterkaj** |
| **Supervisor:** | **Lucy Poxon** |
| **Student:** | **Mairtin McDermott** |
| **Course:** | **Prof Doc Counselling** |
| **Title of proposed study:** | **A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide.** |

## Checklist

(Optional)

| | YES | NO | N/A |
|---|---|---|---|
| Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.) | ☐ | ☐ | ☐ |
| Detailed account of participants, including inclusion and exclusion criteria | ☐ | ☐ | ☐ |
| Concerns regarding participants/target sample | ☐ | ☐ | ☐ |
| Detailed account of recruitment strategy | ☐ | ☐ | ☐ |
| Concerns regarding recruitment strategy | ☐ | ☐ | ☐ |
| All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.) | ☐ | ☐ | ☐ |
| Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample | ☐ | ☐ | ☐ |
| Clear and detailed outline of data collection | ☐ | ☐ | ☐ |

| | | | |
|---|---|---|---|
| Data collection appropriate for target sample | ☐ | ☐ | ☐ |
| If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point | ☐ | ☐ | ☐ |
| If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation | ☐ | ☐ | ☐ |
| Concerns regarding data storage (e.g., location, type of data, etc.) | ☐ | ☐ | ☐ |
| Concerns regarding data sharing (e.g., who will have access and how) | ☐ | ☐ | ☐ |
| Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored) | ☐ | ☐ | ☐ |
| If required, General Risk Assessment form attached | ☐ | ☐ | ☐ |
| Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise | ☐ | ☐ | ☐ |
| Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise | ☐ | ☐ | ☐ |
| If required, Country-Specific Risk Assessment form attached | ☐ | ☐ | ☐ |
| If required, a DBS or equivalent certificate number/information provided | ☐ | ☐ | ☐ |
| If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.) | ☐ | ☐ | ☐ |
| All relevant information included in the participant information sheet (PIS) | ☐ | ☐ | ☐ |
| Information in the PIS is study specific | ☐ | ☐ | ☐ |
| Language used in the PIS is appropriate for the target audience | ☐ | ☐ | ☐ |
| All issues specific to the study are covered in the consent form | ☐ | ☐ | ☐ |
| Language used in the consent form is appropriate for the target audience | ☐ | ☐ | ☐ |
| All necessary information included in the participant debrief sheet | ☐ | ☐ | ☐ |
| Language used in the debrief sheet is appropriate for the target audience | ☐ | ☐ | ☐ |
| Study advertisement included | ☐ | ☐ | ☐ |
| Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.) | ☐ | ☐ | ☐ |

## Decision options

| | |
|---|---|
| **APPROVED** | Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment. |
| **APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES** | In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **<u>before</u>** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of |

|  |  |
|---|---|
|  | this decision notice to the supervisor. The supervisor will then forward the student’s confirmation to the School for its records.<br>**Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials. |
| **NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** | In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.<br>**Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate’s ability to ethically, safely and sensitively execute the study. |

## Decision on the above-named proposed research study

|  |  |
|---|---|
| **Please indicate the decision:** | APPROVED - MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES |

## Minor amendments

Please clearly detail the amendments the student is required to make

**Section 5.1 Consider participants revealing potentially worrying / concerning information, what will you do, have you got a protocol for referral to appropriate services?**
**Section 5.2 There are always risks to the researcher when interacting with participants you are conducting online interviews, however this will involve some level of exchange of information, consider the professionalism you will adopt to ensure minimisation of risks such are protecting your privacy data exchange etc.**

## Major amendments

Please clearly detail the amendments the student is required to make

## Assessment of risk to researcher

| | | |
|---|---|---|
| **Has an adequate risk assessment been offered in the application form?** | **YES**<br>☒ | **NO**<br>☐ |
| | If no, please request resubmission with an **adequate risk assessment.** | |
| **If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:** | | |
| **HIGH** | Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics. | ☐ |
| **MEDIUM** | Approve but include appropriate recommendations in the below box. | ☐ |
| **LOW** | Approve and if necessary, include any recommendations in the below box. | ☒ |
| **Reviewer recommendations in relation to risk (if any):** | Please insert any recommendations | |

## Reviewer's signature

| | |
|---|---|
| **Reviewer:**<br>(Typed name to act as signature) | **Dr Fiorentina Sterkaj** |

| | |
|---|---|
| **Date:** | **28/10/2022** |

***This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee***

**RESEARCHER PLEASE NOTE**

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

## Confirmation of minor amendments

(Student to complete)

**I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data**

| | |
|---|---|
| **Student name:**<br>(Typed name to act as signature) | **Mairtin McDermott** |
| **Student number:** | **2069674** |
| **Date:** | **27/11/2022** |

***Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required***

University of East London

# School of Psychology Ethics Committee

# REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

**Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology**

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

## How to complete and submit the request

| | |
|---|---|
| 1 | Complete the request form electronically. |
| 2 | Type your name in the 'student's signature' section (page 2). |
| 3 | When submitting this request form, ensure that all necessary documents are attached (see below). |
| 4 | Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk |
| 5 | Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation. |
| 6 | Recruitment and data collection are **not** to commence until your proposed amendment has been approved. |

## Required documents

| | |
|---|---|
| A copy of your previously approved ethics application with proposed amendment(s) added with track changes. | **YES**<br>☒ |
| Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc. | **YES**<br>☒ |
| A copy of the approval of your initial ethics application. | **YES**<br>☒ |

| Details | |
|---|---|
| **Name of applicant:** | **Mairtin McDermott** |
| **Programme of study:** | **Professional Doctorate in Counselling Psychology** |
| **Title of research:** | **A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide.** |
| **Name of supervisor:** | **Dr Lucy Poxon** |

## Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

| **Proposed amendment** | **Rationale** |
|---|---|
| Participants will be recruited through multiple channels. I will attend meetings of the South Thames Sickle Cell & Thalassaemia Network, a support group for those with Sickle Cell Disease, to present my proposal, receive feedback and invite participation. I will also ask the network to promote the study through their social media channels. I will also approach social media groups, for example forums for people with sickle cell disease on Facebook via their administrator to ask for consent to advertise the research. I will also recruit through UEL; I will ask the UEL Alumni Network to promote the study through their social media channels and will use 'research participation' moodle sites and teams or channels within a team as recommended by the UEL School of Psychology. I will also post details of the study on my LinkedIn profile and will speak with my cohort at UEL and ask them to forward the study advertisement to those who they feel might be eligible. Finally, I will also ask all participants in the study to recommend other participants they feel might | Initial attempts to recruit participants, through attending a meeting of the South Thames Sickle Cell and Thalassaemia Network were not successful. I have attended one meeting, but no received no interest from potential participants. Neither did I receive any interest through my cohort sharing details of the study. I had originally planned to ask the Sickle Cell Society to help with recruitment, but they have since informed me that they do not promote studies that they do not fund. I therefore propose to additionally recruit through approaching sickle cell disease patient forums on social media, UEL social media accounts and university recruitment pathways recommended by the School of Psychology and through promoting the study on my LinkedIn page. |

| | |
|---|---|
| be eligible and willing to participate. I will invite these participants to forward the study advertisement to their contacts through email. I will conduct all interviews remotely using MS Teams which will remove a significant barrier to participation, as well as being ethically more appropriate for this population given their clinical vulnerability (see below). All participants will also be offered a voucher worth £40 for participation. | |
| All participants will also be offered a voucher worth £40 for participation. | As above, recruitment has not been successful so far using a £20 voucher as an incentive for participation. I therefore propose to increase the incentive to £40 in an attempt to encourage participants to come forward. |
| Proposed amendment | Rationale for proposed amendment |
| Proposed amendment | Rationale for proposed amendment |

## Confirmation

| | | |
|---|---|---|
| **Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?** | **YES**<br>☒ | **NO**<br>☐ |

## Student's signature

| | |
|---|---|
| **Student:**<br>(Typed name to act as signature) | **Mairtin McDermott** |
| **Date:** | **25/02/2023** |

## Reviewer's decision

| | | |
|---|---|---|
| **Amendment(s) approved:** | **YES**<br>☒ | **NO**<br>☐ |
| **Comments:** | **Please ensure that permission is sought before advertising on social media/online platforms. Please ensure control/monitoring procedures are put in place to ensure that no identifiable information is shared publicly through snowballing approach to recruitment.** | |

| | |
|---|---|
| **Reviewer:**<br>(Typed name to act as signature) | **Trishna Patel** |
| **Date:** | **02/03/2023** |

University of East London

## School of Psychology Ethics Committee

## REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

**Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology**

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

## How to complete and submit the request

| | |
|---|---|
| 1 | Complete the request form electronically. |
| 2 | Type your name in the 'student's signature' section (page 2). |
| 3 | When submitting this request form, ensure that all necessary documents are attached (see below). |
| 4 | Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk |
| 5 | Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation. |
| 6 | Recruitment and data collection are **not** to commence until your proposed amendment has been approved. |

## Required documents

| | |
|---|---|
| A copy of your previously approved ethics application with proposed amendment(s) added with track changes. | **YES**<br>☒ |
| Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc. | **YES**<br>☒ |
| A copy of the approval of your initial ethics application. | **YES**<br>☐ |

## Details

| | |
|---|---|
| **Name of applicant:** | **Mairtin McDermott** |
| **Programme of study:** | **Professional Doctorate in Counselling Psychology** |
| **Title of research:** | **A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide.** |
| **Name of supervisor:** | **Dr Lucy Poxon** |

## Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

| **Proposed amendment** | **Rationale** |
|---|---|
| Change title of study to: A thematic analysis of encounters between those with sickle cell disease and their healthcare professionals where medication is discussed. | To more accurately reflect the study results. |
| Proposed amendment | Rationale for proposed amendment |
| Proposed amendment | Rationale for proposed amendment |
| Proposed amendment | Rationale for proposed amendment |

## Confirmation

| | | |
|---|---|---|
| **Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?** | **YES**<br>☒ | **NO**<br>☐ |

## Student's signature

| | |
|---|---|
| **Student:**<br>(Typed name to act as signature) | **Mairtin McDermott** |
| **Date:** | **12/07/2024** |

| Reviewer's decision | | |
|---|---|---|
| **Amendment(s) approved:** | **YES**<br>☒ | **NO**<br>☐ |
| **Comments:** | | |
| **Reviewer:**<br>(Typed name to act as signature) | **Trishna Patel** | |
| **Date:** | **15/07/2024** | |

## Appendix D: Debrief sheet

# THANK YOU FOR PARTICIPATING

I would like to remind you that your participation in this study was completely voluntary and that your confidentiality and anonymity is assured in the final thesis and any other publications that are produced from these data. If you wish for your data to be withdrawn from the study, please send me an email within 3 weeks of your interview being completed. At this point, data analysis will have commenced, and withdrawal will not be possible.

If you were upset, disturbed or distressed by participation in this study or found out information about yourself that is upsetting, disturbing, or distressing, we encourage you to make contact with one of the following agencies:

- Sickle Cell Disease helpline: Sickle Cell society: 020 8961 7795, www.sicklecellsociety.org
- List of psychologists in your area: http://www.bps.org.uk/psychology-public/find-psychologist/find-psychologist
- The Samaritans: 08457 90 90 90 or www.samartians.org

Also, if you have any questions or concerns about this study, please contact either myself, Máirtín McDermott, or my supervisor, Dr Lucy Poxon at the details provided below.

Máirtín McDermott
Counselling Psychologist in Training
University of East London
Email: U2069674@uel.ac.uk

Dr Lucy Poxon
Senior Lecturer
University of East London
Email: l.poxon@uel.ac.uk

University of East London

**Pioneering Futures** Since 1898

## Appendix E: Participant Information Sheet

# PARTICIPANT INFORMATION SHEET

## A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide

**Contact person: Máirtín McDermott**
**Email: u2069674@uel.ac.uk**

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

### Who am I?

My name is Máirtín McDermott. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Professional Doctorate in Counselling Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

### What is the purpose of the research?

I am conducting research into people with sickle cell disease's experiences of medical encounters where they have been recommended to take hydroxycarbamide. I am interested in speaking to them about these experiences, whether or not they subsequently decided to take hydroxycarbamide.

In most research studies that have been conducted so far, deciding not to take a medicine, or not taking a medication as recommended, has been defined and examined as a behavioural problem and the reasons for non-adherence focus primarily on factors within the non-adherent person, for example, their beliefs about the medicine, motivation to take the medicine etc… However, other research and theories have identified the crucial role of the patient's experience with the medical encounter, and in particular their relationship with the healthcare provider. To my knowledge, this issue has not been examined in those with sickle cell disease in the UK and therefore the results of this study could shed some insight into these important experiences.

**Why have I been invited to take part?**

To address the study aims, I am inviting those with sickle cell disease who have been recommended to take hydroxycarbamide and who live in the UK. If you meet these criteria, you are eligible to take part in the study.

It is entirely up to you whether you take part or not, participation is voluntary.

**What will I be asked to do if I agree to take part?**

If you agree to take part, you will be asked to take part in one interview, conducted online using Microsoft Teams. You do not need to have MS Teams installed on your computer to take part. Interviews will last for approximately one hour and will be like having an informal chat, there are no right or wrong answers, I am interested in learning more about your experiences. I will ask you about your experiences of being recommended to take hydroxycarbamide by a healthcare provider, what you think about your health care providers and about your current use of hydroxycarbamide (if at all). Interviews will be audio recorded.

As a thank you for participation, I will give those who complete the interview an all4one voucher worth £40 which can be spent at a wide range of retailers (see https://www.one4all.com/new-where-to-spend for details).

**Can I change my mind?**

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw from the interview, you can do so by letting me know at any time point during the interview. If you withdraw, your data will not be used as part of the research.

Separately, you can also email me to request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 3 weeks of the data being collected after which point the data analysis will begin, and withdrawal will not be possible.

**Are there any disadvantages to taking part?**

Aside from giving me your time I do not anticipate many potential disadvantages to taking part in this research. Although it is unlikely that we will discuss anything that might cause you to become upset, prior to starting the interview, I will ask you how you would like the interview to be handled should you become distressed, and how I might be able to tell. You will also be able to take a break at any point during the interview, and as mentioned above you will be able to stop the interview and withdraw should you want to. You are also not obliged to answer any question you do not want to.

**How will the information I provide be kept secure and confidential?**
Interviews will be audio-recorded and then transcribed. Information that you provide in the interview will be pseudonymised upon transcription, meaning that your name and any other potentially identifiable information divulged during interviews, e.g. jobs, addresses, names of others etc…, will be changed to protect confidentiality. It will not be possible to identify you from the final thesis or any other output created from the research. Audio recordings will be destroyed once transcription has taken place.

The data generated in the course of the research will be retained in accordance with the University's Data Protection Policy. The research data will be stored safely on a password protected computer. The raw (i.e. not pseudonymised ) research data will not be shared with individuals outside of the research team. However the pseudonymised data will also be seen by my research supervisor and examiners. Your personal contact details will be retained for one year following study end to allow results to be shared with you should you wish. Long term I will store the pseudonymised data in the UEL research repository, https://repository.uel.ac.uk . Anonymised transcripts and thematic codes will be stored here for five years and backed up on a password protected personal portable drive, after which they will be reviewed for further retention or deletion.

Your confidentiality will be maintained unless a disclosure is made that indicates that you or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

**What will happen to the results of the research?**
The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings may also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations or talks. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

You will be given the option to receive a summary of the research findings once the study has been completed for which your email address will need to be provided and retained.

**Who has reviewed the research?**

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

**Who can I contact if I have any questions/concerns?**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

**Máirtín McDermott**
**u2069674@uel.ac.uk**

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Lucy Poxon, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: L.Poxon@uel.ac.uk

**or**

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

**Thank you for taking the time to read this information sheet**

## Appendix F: Consent Form

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

### A thematic analysis of experiences of medical encounters in those with sickle cell disease and the role of these experiences in adherence to hydroxycarbamide

**Contact person: Máirtín McDermott**
**Email: u2069674@uel.ac.uk**

| | **Please initial** |
|---|---|
| I confirm that I have read the participant information sheet dated 14/10/2022 (version 1) 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 had these answered satisfactorily. | |
| I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage. | |
| I understand that if I withdraw during the study, my data will not be used. | |
| I understand that I have 3 weeks from the date of the interview to withdraw my data from the study. | |
| I understand that the interview will be recorded using Microsoft Teams. | |
| I understand that my personal information and data, including audio recordings from the research will be securely stored 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 would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to. | |
| I agree to take part in the above study. | |

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………………………………

Participant's Signature

…………………………………………………………………………………………

Researcher's Name (BLOCK CAPITALS)
MÁIRTÍN MCDERMOTT
…………………………………………………………………………………………

Researcher's Signature

Redacted for copyright reasons

…………………………………………………………………………………………

Date

…………………………………………………………………………………………

## Appendix G: Familiarisation Notes

### First read through completed on 2nd November 2023, second completed on 21st December 2023.

I listened through all interviews once and read through all transcripts once.

My background to this project is that I am interested in how participants experience the conversations they have with their healthcare providers, primarily their consultants, about hydroxycarbamide, with a particular focus on their experience of the person, and their relationship with that person. I am interested in attachment processes and so these are generally to the forefront of my mind. My background is different, however, with lots of previous research done looking at behaviour using primarily social-cognitive models and so these also come to mind when I'm reading through and listening to these transcripts.

For the project as a whole, I need to remember to reflect on my role in the interviews and how participants are relating with me and responding to what I am asking them. Several of the participants seemed surprised when I asked them about a relationship with their doctor, as if it hadn't occurred to them that they had one. Participant six explicitly says that she had 'never thought' about relationships with her doctors before. Other participants seemed to be thinking about things for the first time in response to my questions, the relationship, therefore, may have become more important as a result of my questioning.

I need to remember not to conclude anything about the importance of inter-psychic over intra-psychic variables and processes. Although some intra-psychic stuff comes out, the overall theme of the conversation was not about this.

Almost the first thing that struck me when reading and listening back was how everybody's story is very different in terms of their illness, e.g. when they were diagnosed, how ill and distressed they are in terms of symptoms and side effects, how they interact with their doctor and what their experiences have been with healthcare. I need to be mindful to acknowledge and reflect this variability when writing up.

Against that, there is a common thread through all of the participants' stories about being vulnerable, in pain and distress and in need of something from someone else, I feel therefore that relationships, help seeking behaviour and attachment are fundamentally important here.

I have identified some preliminary themes that I feel may be included in the final results: Attachment strategies within participants, for example down-regulating distress and not seeking help (possibly leading to feelings of abandonment and neglect);

What it's like to experience a secure base, feelings of containment and feeling held and how this plays out in deciding to take a medication and continue to take it;

Relationships beyond doctor-patient and when these come into play, for example consulting with wider family, other patients and social media in trying to understand either decision making or sense making of symptoms and side effects;
Mentalisation, sense making of own experience and being offered a model of experience (e.g. of side effects, of how hydroxycarbamide will help) and this either being rejected or accepted).

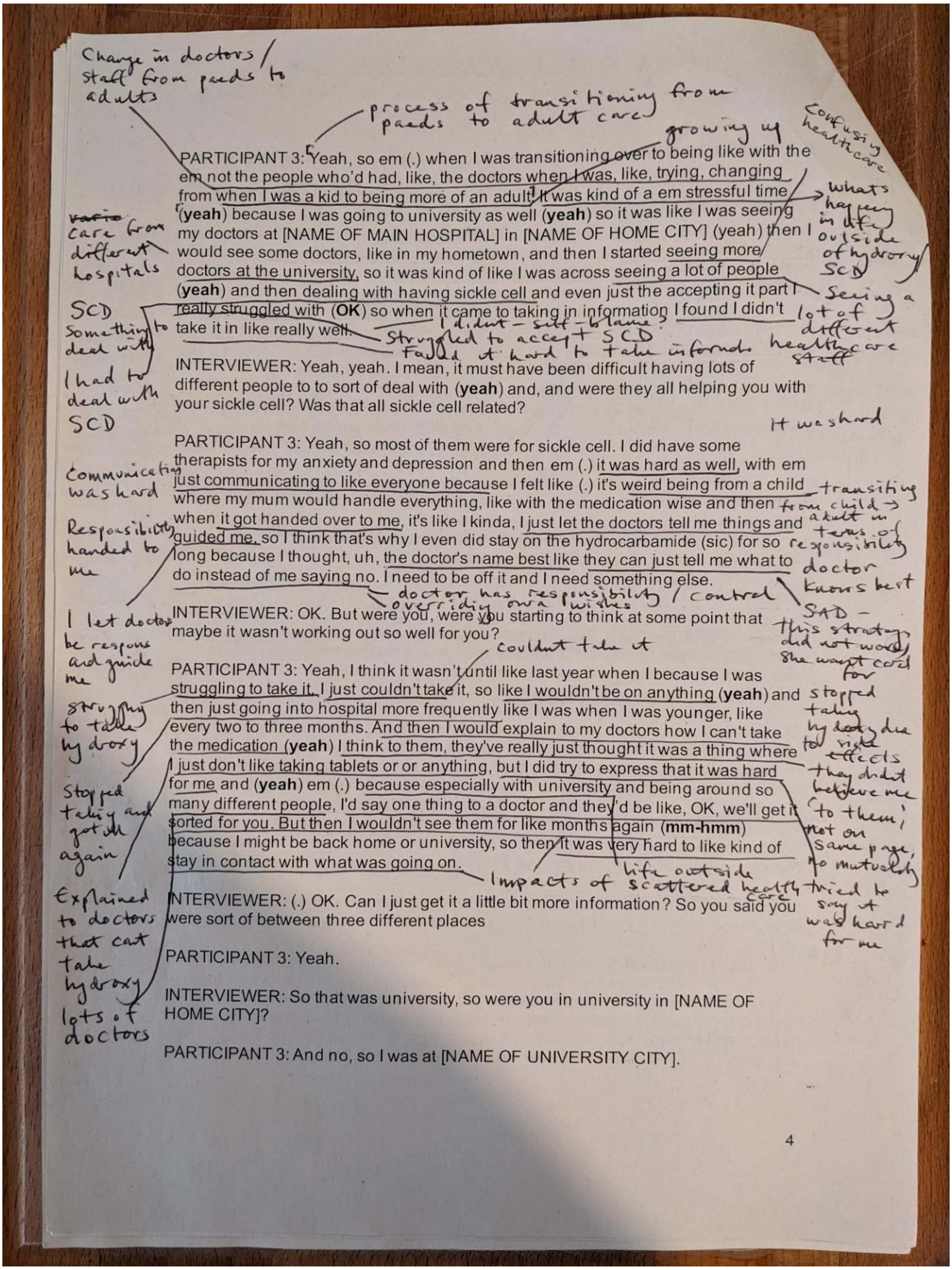
Conversations about medication, to take or not to take, whether initially or to continue;
The impact of the healthcare system, whether a single doctor is seen regularly or a different doctor each time, the impact of this on relationship forming, and subsequent impact on help seeking and interpretation of symptoms.

There is also a complexity in the process where both inter- and intra-psychic variables interact with each other. For example continuing medication use being a result of someone with a particular attachment strategy, with specific symptoms and in or not in a state of distress encounters a doctor who is more or less attuned to them and prescribes a medication which either does or does not alleviate symptoms and does or does not produce side effects which are or are not attributed to the medication, which the doctor then responds to and does or does not contain any distress and ambivalence.

Although I can probably identify some variables and processes that appear to be in play, as mentioned above ultimately I need to put the participants at the centre of the story, remember the scope of this project and ultimately reflect their individuality and uniqueness, whilst also describing some processes that may be clinically important and worthy of further investigation. I've always thought that this would be an interesting and worthwhile project to do, that to shine a light on some of these relational processes would be helpful for those who work in this area and would like their patients to use these medicines that they know would be helpful for them.

This attitude was bolstered by an encounter I had with a haematology consultant I met at one of the support groups where I tried to recruit participants. I don't think she understood the full scope of the project, feeling instead that it was about trying to increase uptake of and adherence to these medicines and announced to the group that she felt it was an important project to take part in, because, and this was delivered slightly condescendingly, she couldn't understand how she can spend her days talking to people about how effective these medicines are and still they don't decide to take them. I remember thinking, well if this is how you speak to your patients, I'm not surprised.

## Appendix H: Transcript showing initial coding process



Change in doctors / staff from paeds to adults

process of transitioning from paeds to adult care

growing up

Confusing healthcare

PARTICIPANT 3: Yeah, so em (.) when I was transitioning over to being like with the em not the people who'd had, like, the doctors when I was, like, trying, changing from when I was a kid to being more of an adult. It was kind of a em stressful time (**yeah**) because I was going to university as well (**yeah**) so it was like I was seeing my doctors at [NAME OF MAIN HOSPITAL] in [NAME OF HOME CITY] (yeah) then I would see some doctors, like in my hometown, and then I started seeing more doctors at the university, so it was kind of like I was across seeing a lot of people (**yeah**) and then dealing with having sickle cell and even just the accepting it part I really struggled with (**OK**) so when it came to taking in information I found I didn't take it in like really well.

~~vario~~ care from different hospitals

whats happening in life outside of hydroxy/SCD

Seeing a lot of different healthcare staff

SCD Something to deal with

I had to deal with SCD

I didnt – self-blame?

Struggled to accept SCD

Found it hard to take informat.

INTERVIEWER: Yeah, yeah. I mean, it must have been difficult having lots of different people to to sort of deal with (**yeah**) and, and were they all helping you with your sickle cell? Was that all sickle cell related?

It was hard

PARTICIPANT 3: Yeah, so most of them were for sickle cell. I did have some therapists for my anxiety and depression and then em (.) it was hard as well, with em just communicating to like everyone because I felt like (.) it's weird being from a child where my mum would handle everything, like with the medication wise and then when it got handed over to me, it's like I kinda, I just let the doctors tell me things and guided me, so I think that's why I even did stay on the hydrocarbamide (sic) for so long because I thought, uh, the doctor's name best like they can just tell me what to do instead of me saying no. I need to be off it and I need something else.

Communicating was hard

Responsibility handed to me

transiting from child → adult in terms of responsibility

doctor knows best

doctor has responsibility / control

overriding own wishes

I let doctor be respons and guide me

SAD – this strategy did not work, she wasn't cared for

INTERVIEWER: OK. But were you, were you starting to think at some point that maybe it wasn't working out so well for you?

couldnt take it

PARTICIPANT 3: Yeah, I think it wasn't until like last year when I because I was struggling to take it. I just couldn't take it, so like I wouldn't be on anything (**yeah**) and then just going into hospital more frequently like I was when I was younger, like every two to three months. And then I would explain to my doctors how I can't take the medication (**yeah**) I think to them, they've really just thought it was a thing where I just don't like taking tablets or or anything, but I did try to express that it was hard for me and (**yeah**) em (.) because especially with university and being around so many different people, I'd say one thing to a doctor and they'd be like, OK, we'll get it sorted for you. But then I wouldn't see them for like months again (**mm-hmm**) because I might be back home or university, so then it was very hard to like kind of stay in contact with what was going on.

struggling to take hydroxy

Stopped taking and got ill again

Explained to doctors that cant take hydroxy

lots of doctors

stopped taking hydroxy due to side effects

they didnt believe me 'to them'; not on same page, no mutuality

tried to say it was hard for me

Impacts of scattered health care

life outside

INTERVIEWER: (.) OK. Can I just get it a little bit more information? So you said you were sort of between three different places

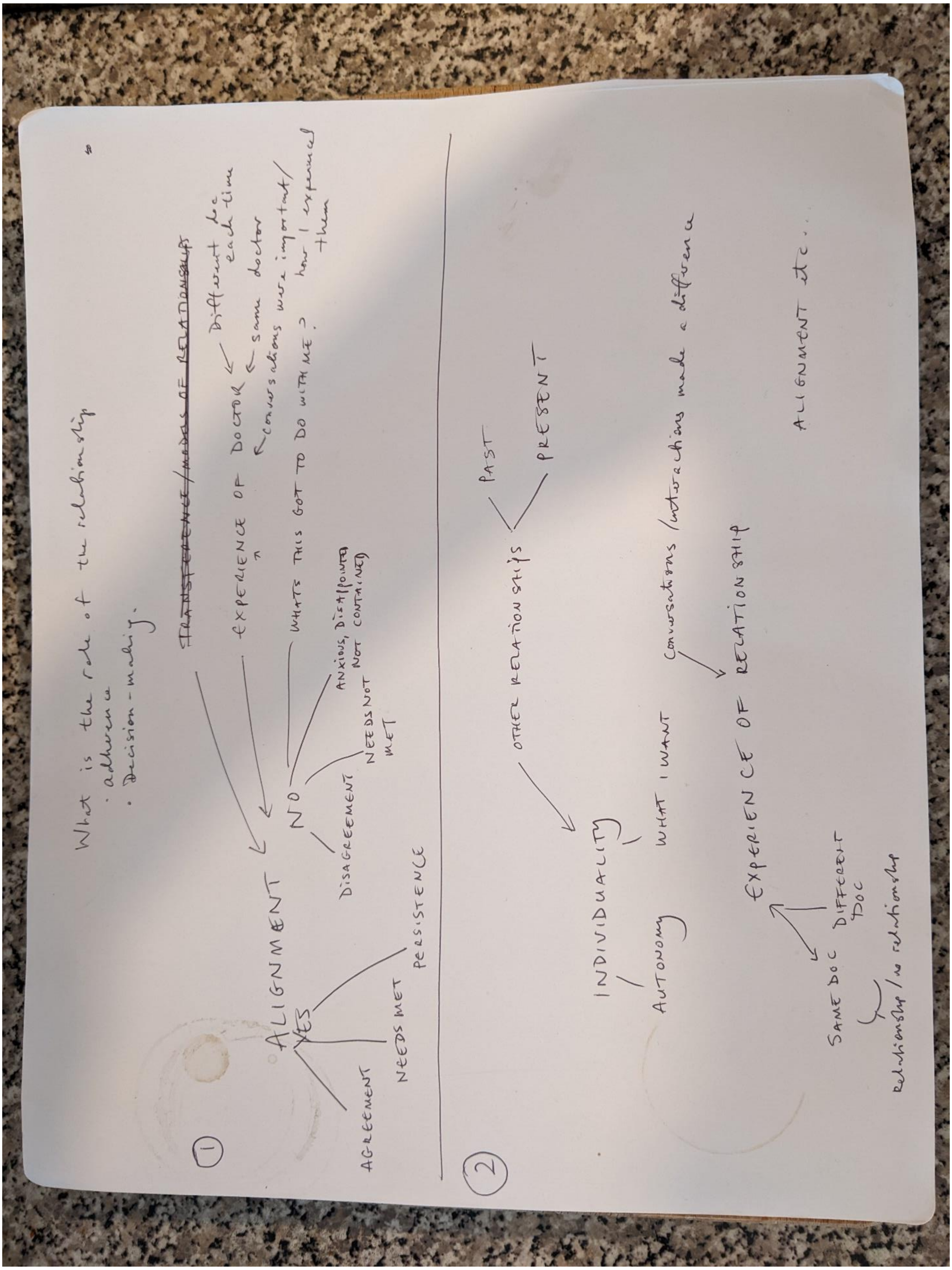
PARTICIPANT 3: Yeah.

INTERVIEWER: So that was university, so were you in university in [NAME OF HOME CITY]?

PARTICIPANT 3: And no, so I was at [NAME OF UNIVERSITY CITY].

4

## Appendix I: Example of an early visual map of themes



## Appendix J: Final themes with component codes

| **Theme 1: Perceptions of vulnerability underpin the relationship** | |
|---|---|
| **Subtheme** | **Codes** |
| *"A lot of people don't know how to manage it"* | People with SCD are vulnerable<br>SCD is a rare disease<br>SCD is a serious condition |
| *People with SCD rely on their doctors to survive* | People with SCD are vulnerable and rely on medics to survive<br>You need someone you can trust with your life<br>Some doctors are better than others |
| *"The pain is a killer", feeling vulnerable due to physical symptoms* | I was in a bad place when hydroxycarbamide was recommended to me.<br>Not ill before hydroxy was recommended<br>Awareness of own vulnerability in relation to age<br>Taking hydroxy made me feel ill<br>I've taken hydroxy and it's hard |
| **Theme 2: Past relationships and templates impacting on the present** | |
| *"My whole life I had looked to older people to help me make my health decisions"* | When I was younger, my parents managed my SCD<br>When I was younger, I didn't question things<br>Doctors as authority figures<br>Realising that roles and responsibilities change as I get older<br>Transition to me being responsible from them was not smooth<br>I've had no choice but to take care of myself<br>I do things differently now due to bad experiences<br>Following medical advice is morally correct<br>I didn't connect with them because it felt like a tick box thing |
| *Unconscious templates in action* | Having a different relationship with my doctor than with my family<br>The way they responded was unexpected<br>I keep up my end of the bargain.<br>It's the system's fault, not my doctor's |

| | |
|---|---|
| | They hadn't done enough to convince me<br>It was an easy choice to take hydroxy<br>After the doctor's spiel, I felt like I should take it<br>I feel guilty when I bother them<br>My doctor is trustworthy.<br>Taking comfort in their professionalism (you want your doctor to be professional)<br>Wrestling with my doctor<br>I demand to be at the centre of my care |
| **Theme 3: Maintaining independence** | |
| *"From a very early age I spent a lot of time trying to understand how my body works"* | I know my SCD<br>I may be more knowledgeable and capable with regards to SCD than others<br>I do my own research<br>Building hydroxy into my lifestyle<br>I don't like the idea of taking medication every day<br>I don't want to go on medication and never come off<br>You need to stay connected to your own body |
| *"I'm the one who is going to be taking their medication"* | Ultimate responsibility for my body and care is mine<br>I went against my own wishes<br>I can take care of myself<br>Being healthy is important<br>Blaming myself when things go wrong.<br>Receiving support from others with SCD<br>Parents/ family supportive involvement in my healthcare as an adult |
| **Theme 4: The adequacy of the response** | |
| *"I don't think that there would be any reasons for him to recommend something that's not good for me".* | I don't think that there would be reasons for him to recommend something that's not good for me<br>My doctor taking control meant I had less to worry about<br>I felt relief when my doctor offered a solution<br>You guys should know how to treat me but you don't<br>Feeling lost because no solutions are being offered.<br>Questioning my doctor's motives |

| | |
|---|---|
| | I found it hard to take in information<br>It did not feel like a safe space.<br>Seeing a different doctor every time causes problems<br>Having a regular doctor<br>I was seeing different doctors all of the time and it was stressful<br>Not having regular appointments is making me feel worried<br>Feeling reassured<br>Feeling understood<br>Feeling listened to<br>I didn't feel heard<br>They didn’t understand |
| *"I need to see how it would benefit me personally"* | It's important that your doctor knows me medically<br>What's this got to do with me?<br>Medical advice was not based on me and my body<br>I want to be seen as an individual<br>It makes a difference when things are sold as personal<br>Thinking of the science/ medicine, not the person in front of you |
| *"As he continued to talk, I felt like he cared"* | My doctor monitors me<br>My doctor spoke to my family<br>Receiving support from your doctor<br>My doctor being proactive/ going above and beyond<br>My doctor took action in response to my concerns<br>As he continued to talk, I felt like he cared<br>Receiving responsive care in relation to my needs at the time<br>Doctor's support helped me to persevere<br>Importance of doctor's knowledge<br>the doctor had talked to me about the side effects and I was ready for them<br>The conversations helped me through the tough times<br>Not receiving care appropriate to my needs<br>Doctor did not help me to persevere through discomfort of side effects |

## Appendix K: 15-point checklist for good reflexive thematic analysis (from Braun & Clarke, 2002, p269)

| No | Process | Criteria |
|---|---|---|
| 1 | Transcription | The data have been transcribed to an appropriate level of detail; all transcripts have been checked against the original recordings for 'accuracy'. |
| 2 | Coding and theme development | Each data item has been given thorough and repeated attention in the coding process. |
| 3 |  | The coding process has been thorough, inclusive and comprehensive; themes have not been developed from a few vivid examples (an anecdotal approach). |
| 4 |  | All relevant extracts for each theme have been collated. |
| 5 |  | Candidate themes have been checked against coded data and back to the original dataset. |
| 6 |  | Themes are internally coherent, consistent and distinctive; each theme contains a well-defined central organising concept; any subthemes share the central organising concept of the theme. |
| 7 | Analysis and interpretation – in the written report | Data have been analysed – interpreted, made sense of – rather than just summarised, described or paraphrased. |
| 8 |  | Analysis and data match each other – the extracts evidence the analytic claims. |
| 9 |  | Analysis tells a convincing and well-organised story about the data and topic; analysis addresses the research question. |
| 10 |  | An appropriate balance between analytic narrative and data extracts is provided. |
| 11 | Overall | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase, or giving it a once-over-lightly (including returning to earlier phases or redoing the analysis if needs be). |
| 12 | Written report | The specific approach to thematic analysis, and the particulars of the approach, including theoretical positions and assumptions are clearly explicated. |
| 13 |  | There is a good fit between what was claimed, and what was done -i.e. the described method and reported analysis are consistent. |
| 14 |  | The language and concepts used in the report are consistent with the ontological and epistemological positions of the analysis. |
| 15 |  | The researcher is positioned as *active* in the research process; themes do not just 'emerge'. |