SICKLE CELL DISEASE IN YOUNG MEN, AND ITS IMPACT ON RELATIONSHIPS

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ABSTRACT

Background:

Sickle Cell Disease (SCD) is a common genetic blood disorder with short and long-term physical and mental health effects. This population faces additional challenges such as stigma and health inequities, but also challenges within relationships, due to their condition. However, very little is known about how SCD affects romantic relationships, and specifically men's perspectives on this.

Method:

A qualitative methodology, using semi-structured interviews, was utilised to explore how SCD impacts romantic relationships for men in the UK. Seven men aged between 20-39 were recruited to share their views and experiences. Thematic Analysis was employed to analyse the data.

Results:

Three interconnected themes were developed: 'societal and cultural norms concerning romantic relationships', 'lack of awareness and understanding, misconceptions and stigma around SCD', and 'disclosing SCD within a romantic relationship'. Within these themes, topics around reproductive decisions, masculinity, sexual relationships, being a burden, and adapting and acceptance of SCD, were discussed.

Conclusions and Implications:

SCD impacts men's romantic relationships in a host of areas. Supporting men with these difficulties may include change at individual level, for instance healthcare professionals using a holistic approach, including psychological therapy to support these men. In addition, broader/societal level approaches such as increasing awareness, knowledge and understanding around SCD, in order to reduce the detrimental effects felt by these men, and enabling them to live more fulfilling and satisfying lives.

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1. INTRODUCTION

Sickle Cell Disease (SCD) is a serious, genetic health condition, with significant physical and mental health consequences. Despite its prevalence, there is a notable lack of awareness and understanding about the condition within the general population, which contributes to the stigma and health inequalities faced by individuals with SCD. An important source of support for these individuals are the people within their close networks; however, research into the psychosocial impact of SCD, including its effects on relationships, is scarce. More specifically, there is no existing research on what is arguably the most important relationship in an adults life; romantic relationships. Research has found that romantic relationships are significantly impacted when an individual has a chronic health condition; therefore, it is surprising that no research has previously addressed this within the SCD population. Furthermore, whilst SCD has been found to have differing effects based on gender, research exploring the impact of SCD on men is limited. Consequently, more research is needed in order to hear the voices of men living with SCD, and to gain a better understanding of their needs, particularly on how SCD may impact upon their romantic relationships.

1.1. Sickle Cell Disease

SCD is a haemoglobin disorder inherited from both parents. A single amino acid substitution leads to producing abnormal haemoglobin. When depleted of oxygen, abnormal haemoglobin polymerises, distorting red blood cells to sickle shapes. Sickled cells lack elasticity, causing blockages in blood vessels (vaso-occlusion), which reduces blood flow and causes insufficient oxygen delivery to tissue around the body. This vaso-occlusion within bones causes a symptom of painful crisis (WHO, 2011). Sickled blood cells also have a short life span and are easily destroyed, meaning that the blood is often short of these cells, increasing the likelihood of anaemia. SCD and Sickle Cell Anaemia are often used interchangeably however, the term SCD encompasses three main genotypes of the condition; HbSS, HbSC, and HbS/thal (Ware et al., 2017). In contrast, the term Sickle Cell Anaemia, is use to describe the most common and severely effecting genotype, HbSS. Whilst used interchangeably, the

variations in genotype mean that prognoses for individuals with SCD and Sickle Cell Anaemia are often different.

1.1.1. Incidence rates

SCD most commonly affects African/Caribbean populations (Sickle Cell Society, 2008; WHO, 2016). It is also common in North-Western India, in areas around the Mediterranean, and amongst Hispanic individuals, despite the misconception that SCD is strictly a “Black Disease” (Bediako & Haywood, 2009). These misconceptions contribute to negative consequences for individuals with SCD, including incorrect diagnoses (Rotimi, 2004). Thus, ‘ancestry’ is a significantly better indicator of SCD risk, in comparison to ‘race’ or ‘ethnicity’ (Ali-Khan et al., 2011; Fujimura et al., 2011; Rotimi, 2004).

SCD is currently the most common genetic, chronic blood disorder within the UK (NHS, 2006; Public Health England, 2016; Sickle Cell Society, 2008). In the United Kingdom (UK), it is estimated that there are 13,500 people with SCD, and 250,000 people who are carriers of the sickle cell gene, Sickle Cell Trait (SCT) (NHS, 2006). SCD is most commonly found in Black British African and Black British Caribbean populations within the UK, with lower rates seen within British Indian populations (Hickman et al., 1999). Currently there is no easily accessible cure for the condition, however, stem cell and bone marrow transplants offer a potential cure (NHLBI, 2012).

1.1.2. Clinical Presentation

Clinical severity of SCD varies, depending on the phenotype. Most individuals have intermediate forms of complications, with a minority of people experiencing either minor complications, with no clinical appearance, or severe complications, such as strokes, acute chest syndrome, and/or pulmonary hypertension (Sebastiani et al., 2007; Thomas & Taylor, 2002; WHO, 2016). Other long-term consequences of SCD include chronic organ damage, such as degeneration of kidneys, bones and joints (Charache et al., 1995). Recurrent, painful crises are the most common symptom of SCD; whilst this form of acute pain may require hospitalisation, many individuals try to manage their crises within the community. Crises can occur unpredictably, however individuals’

environment and lifestyle may also trigger their occurrence. Dehydration, stress, extreme temperatures, and infection, may all contribute to the occurrence of a sickle cell crisis (de Montalembert, 2008). Alongside these forms of acute pain, chronic pain is also common (Matthie et al., 2016).

Patients with SCD live under the threat of early and sudden death related to the condition (Thomas & Taylor, 2002). Because of this, SCD has historically been portrayed as a disease of childhood; however, due to medical advancements in high-income countries (Yawn et al. (2014) there has been a decline in SCD-related mortality, with more than 90% of children reaching adulthood (Quinn et al., 2010). This improvement in survival has lead to the attention of increased issues of SCD-related difficulties within adulthood, such as reproductive issues and sexual functioning (Chaturvedi & DeBaun, 2015). Reproductive issues may include delayed puberty, infertility, and pregnancy complications, (Oteng-Ntim et al., 2015; Smith-Whitley, 2014; Zemel et al., 2007). For men, crises and recurring testicular infarction can cause hypogonadism (Li et al., 2003; Parshad et al., 1994). Erectile dysfunction is also common and likely due to recurring flare-ups of priapism, defined as painful, persisting, and unwanted erections, caused by SCD-related crises localised to the penis (Adeyoju et al., 2002; Madu et al., 2014). Furthermore, men may have a lower sperm count and reduced sperm motility, affecting their fertility (Osegbe et al., 1981). For women, previous research has suggested an increased risk of maternal and neonatal complications whilst pregnant (Oteng-ntim et al., 2015).

Berghs et al. (2020) suggest that most research on SCD is ‘gender-blind’, despite important gender-based differences within the effects of, and responses to, SCD. Beyond biological symptoms, Matthie et al. (2020) found that males with SCD reported lower levels of health literacy, fatigue, and pain catastrophising levels in comparison to females, despite experiencing greater SCD-related complications, such as higher pain intensity and disability. Similarly, Knisely et al. (2020) found that males had lower fatigue scores, despite experiencing increased depression in comparison to female participants. Research has also suggested that males experience greater difficulties in relation to social adjustment and behaviour, due to SCD (Hurtig & Park, 1989). In contrast, Asanani et al. (2017) found that females with SCD

experienced a lower quality of life (QOL), in comparison to males, despite having more knowledge about their condition.

Age has also been shown to impact upon the clinical presentation of SCD. Research has shown that the older an individual with SCD is, the more intense and disabling their pain can be (Knisely et al. 2020; Matthie et al. 2020), impacting negatively upon emotional and psychological wellbeing (Caird et al., 2011). Whilst there is evidence to suggest that SCD severity increases with age, it is important to note that non-SCD related pain may also contribute to heightened pain and disability within older SCD populations.

1.2. Psychosocial Consequences

1.2.1. Quality of Life (QOL)

SCD greatly impacts upon individuals' QOL, due to its debilitating symptoms and complications which are often chronic, unpredictable, and present from birth (Chakravorty et al., 2018; Howard et al., 2009; Kulandaivelu et al., 2018; Thomas et al.,1999; Thomas & Taylor, 2002). QOL encompasses individuals' physical and psychological wellbeing, as well as the perceived quality of their environment, education, employment, and relationships (Mann-Jiles & Morris, 2009). The QOL of adults with SCD, has been shown to be poorer in comparison to the UK general population, Jenkinson et al. (1993), and similar to adults living with other long-term health conditions (Adams & Speechley, 1996; Anie et al., 2002). This suggests that individuals' overall QOL should be considered when being treated for SCD, as opposed to professionals holding a solely medical focus, as has previously been the case within the UK (Smith et al., 2008). Indeed, Osunkwo et al. (2020) also found that the primary treatment goal of individuals with SCD globally, was to improve their QOL.

As SCD significantly impacts on a 'normal' developmental trajectory, adolescents often report difficulties forming and maintaining a good QOL, as their desire to be 'normal' and do similar activities to peers without SCD is unattainable (Matthie et al., 2016). Consequently, individuals' social, family, and work lives can be affected, with some individuals describing difficulties completing college degrees, maintaining employment, and developing

relationships (Abimbola, 2016). Physical disability and SCD-related time commitments have been shown to impact upon the QOL of individuals with SCD (Matthie et al., 2016). Furthermore, Thomas & Taylor (2002) found that the drive to live a 'normal' life, and not be reminded of SCD, can also cause difficulties with activity scheduling, resulting in individuals over-exerting and triggering crises. Jones et al. (2021) similarly found that individuals with chronic pain often chose not to disclose their pain to others, in order to appear 'normal' alongside their peers. Authors found that this contributed to increased loneliness and a reduced number of friendships, which in turn led to lower psychological functioning and increased pain. Individuals with SCD have also been found to refrain from disclosing their condition at work and amongst peers, due to comparing themselves negatively alongside their peers, and wanting acceptance (Foster & Ellis, 2018).

1.2.2. Psychological Well-being

Individuals with SCD have been found to experience increased anxiety, depression, social withdrawal, and difficulties with relationships, at work, and within domestic roles (Anie, 2005; Caird et al., 2011; Howard et al., 2009; Zheng et al., 2020). These difficulties have been associated with adjusting to the effects of SCD, managing its social and emotional impacts, and maintaining relationships with healthcare professionals (HCP) (Moos & Schaefer, 1984). Foster & Ellis' (2018) review found that the unpredictability of the condition impacts significantly on QOL, contributing to hopelessness, depression, and suicidal thoughts. Hopelessness, and lower self-esteem have been found to relate to pain, hospitalisation, and interruptions to education and employment (Anie, 2005). These psychological effects of SCD consequently impact upon social activities and relationships, which are essential for positive development (Spirito et al.,1991; Suris et al., 2004; Taylor et al., 2008). Osunkwo et al. (2020) found globally, that SCD had a negative impact on emotional wellbeing, finding associations with depression, anxiety, and reduced educational achievement and employment hours. Nevertheless, research has shown that individuals with SCD exhibit great resilience in the face of these difficulties (Conyards et al., 1980). Better psychological functioning in individuals with SCD is associated with more mastery and control over their condition, resulting in better coping of its negative effects (Howard et al., 2009).

1.2.3. Stereotypes, Prejudice, Stigma, and Identity

Another factor contributing to psychological well-being and overall QOL for individuals with SCD is their perception of themselves. Self-identity is important for individuals with health conditions as it may increase responsibility towards the illness, which in turn may enhance coping (Kamilowicz, 2011). Caird et al. (2011) found that individuals' ability to manage SCD was partially determined by the strength of the individual's sense of self-identity, with participants preferring to define themselves as separate from their condition. Jones et al. (2021) found similar links amongst chronic pain patients; when chronic pain negatively impacted on identity, increases in health-related isolation and internalised stigma were more likely to be experienced, resulting in pain being seen as the key focus of their identity.

Alongside health-related identity, racial identity development is additionally important to consider within the SCD population. Identity development, and how individuals perceive themselves is connected to sociological, political, and historical factors (Thomas & Schwarzbaum., 2010). Therefore, societal perceptions of SCD in the form of stigma and/or racial prejudice and racism, will impact how an individual views their own self-identity (Pierce et al., 2003). Research supports that racial identity impacts upon the views' others hold towards individuals with SCD. Bediako & Moffit. (2011) found that those who perceived race to be associated with SCD, were more likely to endorse negative ratings of individuals with SCD. Individuals with SCD themselves have also attributed the lack of interest in the condition from wider society to it being a 'black and/or minority condition' (Anionwu & Atkin, 2001; Phan, 2020). Furthermore, nearly 100% of individuals with SCD have reported experiencing racism (Bulgin et al., 2018; Mougianis et al., 2020; Royal et al., 2011). Isaac et al's. (2020) recent review suggests that this racism and racial disparities results in worse psychosocial and health outcomes for individuals with chronic illnesses, such as reduced QOL, heightened depression, and increased morbidity and mortality rates (Mougianis et al., 2020). Therefore, the contribution of racial prejudice and discrimination to health disparities may impact both upon individuals' self-perception, and their ability to maintain a good QOL whilst living with SCD (Howard et al., 2009).

Societal stigma can also impact upon the development of self-identity (Goffman, 1963). Stigma can be understood as society singling out 'less dominant' features, and evaluating them as undesirable; consequently, individuals who hold these features are devalued and discriminated against, resulting in unequal health outcomes across different domains.(Brunton, 1997; Link & Phelan, 2001). Health-related stigma refers to social devaluation or disqualification of an individual based on their health-related condition (Weiss et al., 2006). Millen & Walker (2001) found that health-related stigma negatively impacted upon individuals' self-identity, the quality and quantity of their social connections, and their ability to cope and adapt to their health condition, in a sample of individuals with chronic illnesses. SCD-related stigma has also been linked to poor SCD management, including lower initiation of healthcare, increased isolation, reduced self-esteem, and increased mental health difficulties (Jenerette & Brewer, 2010; Martin et al., 2018; Ola et al., 2016; Wakefield et al., 2017). Stigma may further arise in relation to individuals with SCD due to their potential physical differences Gofman (1963), such as delayed sexual development, physical immaturity, and/or jaundiced eyes (Dyson et al., 2012; Erskine, 2011). These individuals can face additional challenges within a range of contexts, including in education, employment, healthcare systems, the wider community, and within their personal relationships.

Individuals with SCD have also reported experiencing health-related stigma from within the healthcare system. For example, healthcare professionals (HCP's) have been reported as referring to individuals with SCD as "substance abusers" and/or "drug seekers" (Bulgin et al., 2018; Campbell et al., 2010; Goffman, 1963; Jenerette et al 2014). Individuals with SCD often experience a lack of understanding, empathy, and knowledge from staff regarding their heightened pain levels, which leads to misconceptions about the level of pain relief required (Thomas & Taylor, 2002). For example, Tanabe et al. (2007) found that individuals with SCD had to wait 90 minutes for their first analgesic to be given. Within Thomas & Taylor's (2002) review; hospitalisation was described as an extremely unpleasant experience by individuals with SCD, due to the lack of understanding from HCPs about individual differences in coping with pain. Research has additionally found that young adults with SCD experience difficulties and delays in accessing healthcare, and face disruptions

to the quality and continuity of their care (Matthie et al., 2016). Disruptions in healthcare have been connected to individuals' experiences of negative interactions with HCPs, as well as fear of future stigmatisation and judgement (O'Connor et al., 2014). Furthermore, research has shown that individuals often experience a lack of involvement of HCPs within their care, receive insufficient information about treatment options, and are consequently faced with poor pain management (Jenerette & Brewer, 2010; Lattimer et al., 2010; Zempsky, 2010). As a result, individuals with SCD often avoid hospitals, except as a last resort, and instead try to self-manage their healthcare by seeking support and information from individuals within their community (Addis et al., 2007; Thomas & Taylor, 2002).

Schools have also been perceived as unsupportive, with school staff described as lacking awareness and consideration of the effects of SCD (Atkin & Ahmad, 2001). Despite their experiences of extreme pain and fatigue, students with SCD have been referred to as 'lazy' by their teachers, due to the stigma surrounding the condition (Bulgin et al., 2018; Royal et al., 2011). Campbell et al. (2010) found that teachers often thought that pain was an excuse for an individual with SCD to avoid mandatory activities. These misperceptions have negative consequences, including on identity development, due to children and young people internalising these perceptions from others and questioning their own abilities. Despite the negative perceptions held by others, students with SCD have been found to perform at their best despite the significant challenges they face, highlighting their resilience (Thomas & Taylor, 2002). SCD-related stigma is also seen within employment. Dyson et al. (2010) found that disclosing SCD was not perceived to improve treatment in the workplace, instead resulting in disabling attitudes and unnecessary attention which exacerbated individuals' 'sickness identity'. SCD-disclosure can therefore have a negative impact on individuals' ability to construct a preferred identity. This sits in contrast with research exploring the impact of disclosure amongst individuals with other health conditions; for example disclosing one's health condition has been shown to result in increased understanding of participants' illness, and increased acceptance and flexibility around illness-related absences. The continuation of stigma following disclosures of SCD-status may be due to persistent racial and/or ethnic prejudice. Foster & Ellis (2018) review

found that when individuals with SCD experienced discrimination and stigma within employment and education, this was believed to be more related to racism as opposed to their illness. Atkin & Ahmad (2001) similarly found that reduced expectations from teachers towards individuals with SCD were perceived to be due to students' African and/or Caribbean descent, as opposed to their SCD.

Individuals with SCD may also experience stigma from close family and friends due to limited understanding of the condition and cultural-specific misconceptions (Phan, 2020). Sankar et al. (2006) found that family and friends of individuals with SCD, perceived families as flawed if a family member had SCD. Similarly, Wesley et al. (2016) found that caregivers of individuals with SCD lacked knowledge of the condition, and reported experiencing internalised stigma such as negative feelings towards having children with SCD. SCD-related stigma within specific communities has also been highlighted within research, with studies showing a lack of desire amongst African American participants wanting to discuss SCD (Burnes et al., 2008; Mayo-Gamble et al., 2019). This negative perception and form of being ostracised, may be internalised effecting self-perception of the individual with SCD. Stigma from family members and romantic partners has been found to impact individuals' willingness to disclose SCD-status, due to fears of being pitied, treated differently, or being discriminated against (Cobo et al., 2013; Cole, 2007; Ola et al., 2016). However Phan (2020) suggests that health-related stigma and lack of knowledge around the condition may occur, in part, due to the invisibility of SCD.

1.3. Coping and Management

1.3.1. Self-Care, Meaning-making, and Acceptance

Notably, the impact of SCD is physical, psychological and social. Research suggests that SCD is primarily self-managed, outside of healthcare settings, where individuals feel more in control (Jenerette et al., 2011; Thomas & Taylor; 2002). However, when healthcare settings are required, research has found that older individuals utilise outpatient clinics more, whilst younger individuals are more likely to utilise emergency departments (Sanders et al., 2010). Younger people with SCD have also been shown to be more likely to cope by

trying to ignore their pain, whereas older individuals are more likely to draw upon prayer and hope. Caird et al. (2011) reported on different practical strategies for managing the physical symptoms of SCD. These include keeping warm, pacing, avoiding over-exertion, eating a healthy diet, and listening to one's own body for signs of needing to reduce stress and slow down. Psychological coping strategies have also been seen to impact pain frequency and severity, and predict healthcare service utilisation for individuals with SCD (Gil et al., 1989; Gil et al.,1992; McDougald et al., 2009).

Disease self-efficacy, defined as the extent to which an individual perceived they can manage their illness and symptoms, has also bee shown to improve psychological and physical health and health-related QOL (Jenerette & Murdaugh, 2008; Goldstein-Leever et al., 2020). Knowledge of SCD has been shown to contribute to disease self-efficacy, due to individuals having a better sense of their condition and their body, greater perceived control, and increased tools to combat their symptoms (Asnani et al., 2017; Caird et al., 2011). Age may also be an important contributing factor to self-efficacy. Matthie et al. (2015) found that older adults with SCD credited self-care for their longevity, with learning from caregivers and increased time living with SCD, both considered central to developing effective self-care. Indeed Jenerette & Lauderdale (2008) and Jenerette et al. (2011), additionally suggest that as individuals age, they gain a better understanding of self-care resources, resulting in improvements in the attainment and use of these strategies and resources.

Making sense of SCD and its condition-specific pain through analogies and personification, has been found to be a helpful coping strategy amongst individuals with SCD, supporting them to change their relationship with the condition (Coleman et al. 2016). Caird et al. (2011) found that participants who developed resilience through finding a more positive meaning or purpose for their SCD experience, reported a greater sense of control over SCD, less negative emotional effects, and increased hope and appreciation for life. Research has additionally found that recognising the genetic causation behind SCD connected individuals to their African ancestry and strengthened their

positive identity, through providing a feeling of belonging and an increased sense of who they are (Sankar et al., 2006; Thomas & Taylor, 2002). This was also seen to reduce feelings of shame. Religion and/or spirituality have also been reported as an important coping mechanisms for individuals with SCD, with increased faith, trust in God, and meaning-making, enhancing the SCD experience (Barbarin & Christian, 1999; Caird et al 2011; Clayton-Jones et al., 2016; Cooper-Effa et al., 2000; Foster & Ellis, 2018; Harrison et al., 2005; Mattis & Jagers, 2001). More specifically, Derlega et al. (2014) found that speaking to God about their SCD resulted in enhanced positive psychological adjustment, greater likelihood of seeking care, and reduced impact of health-related stigma, for individuals with SCD. Foster & Ellis (2018) suggest that this coping mechanism may be of particular importance, due to religion being commonly practiced within African and Caribbean communities.

Research also shows that some individuals with SCD may cope through gradually accepting the currently uncurable nature of their condition and its associated pain, and becoming appreciative of life alongside SCD (Coleman et al., 2016). Caird et al. (2011) found that having lived longer with SCD, older individuals were more likely to move towards accepting their condition, in order to live with its effects. Similarly, Dyson et al. (2010) and Thomas & Taylor, (2002) found that individuals became better at managing their SCD over time, through increased acceptance and integration of SCD within their identity. In line with this research, Foster & Ellis (2018), found that acceptance of SCD was a factor worked towards, or reached, as opposed to something more immediate. Cousins (2017) also found that pain acceptance mediated the relationship between pain burden and QOL in individuals with SCD, highlighting the important role that gradual acceptance plays. As well as acceptance occurring intra-psychologically, external acceptance, achieved by disclosing the condition to others, has been found to reduce the secrecy and stigma surrounding SCD; in turn, this has been shown to strengthen individuals' resilience and coping, through increased meaning-making and positive identity development (Caird et al., 2011). Therefore, the relationship individuals have with their SCD, is seen to predict both their coping and their ability to appreciate life. Individuals with SCD have prominently expressed feeling fortunate for being alive and for the life they live alongside SCD. For some, spreading

awareness of SCD helps them to find a focus and sense of worth and pride. Furthermore, optimism has also been shown to impact upon individuals' management of SCD (Bediako et al., 2007; Bediako & Neblett, 2011); this may connect to individuals' religiosity, with religion shown to be a helpful foundation for optimism (Matthie et al., 2016).

1.3.2. Social Support

Social interactions and relationships have been found to be negatively impacted by SCD. Interruptions to social engagements and interactions are often caused by SCD-related physical restrictions and time commitment, such as time spent in the hospital(Gil et al., 1992; Matthie et al., 2016; Ohaeri et al., 1995; Osunkwo et al., 2020; Reese & Smith, 1997). Social functioning is however additionally associated with physical and psycho-social factors, such as pain severity and impact, employment status, sleep, and depression (Knisely et al., 2020).

Positive relationships with family, romantic partners, peers, HCPs, and colleagues are of huge importance to individuals with SCD, Anie (2005), providing a significant source of support (Derlega et al., 2014). Indeed social support has been found to impact positively on QOL, psychological functioning, and long-term disease management (Burlew et al., 2000; Matthie et al., 2015; Thompson et al., 1992). It is also found to have the most significant impact on self-care, through creating higher self-efficacy and opportunities for collaborative management of the disease (Anie, 2005; Jenerette et al., 2011). Bediako & Neblett (2011) and Bediako et al. (2007) found that support from family and friends acted as a protective factor against perceived SCD-related stigma and discrimination, through reducing the guilt and shame experienced (Campbell et al., 2010; Dyson et al., 2010; Scambler, 2009; Thomas & Taylor, 2002). Social support from others with SCD has additionally been found to buffer the impact of racism on depression (Mougianis et al., 2020). Peer support from individuals with the same health condition has been highlighted as protective within a recent review, resulting in reduced pain and depression (Jones et al., 2021). Support from others has also been found to reinforce positive aspects of one's identity, helping to reduce the 'sickness identity' often experienced by individuals with SCD; instead, social support can enable individuals to explore and commit to alternative identities, whereby they can

focus on ‘living normally’ alongside SCD (Dyson et al., 2010; Lim et al., 2012). However, research has shown that variation in individuals’ contexts impacts upon the quality and accessibility of social support (Caird et al, 2011; Chlebowy & Garvin, 2006). For example, a review by Foster & Ellis (2008) found that females with SCD utilised and benefited from emotional and social support, whereas males found this support ineffective.

Brofenbrenner’s (1979) ‘Ecological Model’ suggests there are different levels of contexts within which an individual can receive support from, ranging from their immediate context, the microsystem, to societal contexts, the macro-system. Within the microsystem, research has more extensively explored the influence of family and peers support on individuals with chronic illnesses (Anderson, 1990; Cohen, 1999; Minuchin et al., 1978). One type of relationship in the microsystem that arguably is of most importance in an adult’s life, including those with chronic illnesses, is romantic relationships.

1.3.2.1 Romantic Relationships:

Romantic relationships are perceived to be different to other types of relationships, due to their intensity, the type of affection, and the sexual intimacy involved (Care Alliance Ireland, 2017; Collins et al., 2009). Within emerging adulthood, increased time is devoted to, and significance placed on, romantic partners (Furman & Buhrmester, 1992; Zimmer-Gembeck, 1999). This period of time is often spent looking for intimate company, emotional security, and thinking about more long-term, romantic commitment (Fincham & Cui, 2011; Simon & Barrett, 2010). Finding romantic and sexual partners is seen as a critical developmental task, contributing to one’s sense of self and identity development (Erikson 1968; Rauer et al., 2013).

The developmental benefits of romantic relationships are also true for chronic illness populations. Romantic relationships have been found to be a central protective factor and a core health determinant for individuals with chronic health conditions, especially within stressful times (Holt-Lunstad et al., 2010; Pietromonaco & Collins, 2017). An absence of romantic relationships has been shown to contribute to reduced well-being across adulthood (Kiecolt-Glaser & Newton, 2001; Rowe, 2018; Taylor et al., 2013); in contrast, satisfying relationships were related to reduced physiological and psychological problems,

and increased coping and life expectancy in individuals with chronic pain and cancer (Kiecolt-Glaser & Newton, 2001; Rowe, 2018; Taylor et al., 2013). Reviews of the literature have also shown that young adults with chronic illnesses, in romantic relationships, are happier and more satisfied with life, experiencing enhanced self-esteem and increased mental and physical health (Gomez-Lopez et al., 2019; Hanghoj & Boisen, 2014; Jamieson et al., 2014). Furthermore, they have been shown to have better adherence to treatment, more social integration skills, and greater educational and vocational success. Rowe (2018) found that cancer patients referred to their romantic partners as their “rock”, through turbulence and uncertainty, providing emotional and practical support.

However, the positive outcomes associated with having a romantic relationship can be seen as simplistic, given that romantic relationships are complex and multifaceted, posing unique challenges for individuals with chronic health conditions. As one of the most central relationships within adult life, romantic relationships can be significantly affected by chronic health conditions, having a large impact upon the diagnosed individual (Kiecolt-Glaser & Newton, 2001). Romantic partners are most likely to cohabit, resulting in increased time co-experiencing the health-condition (Stewart & Brindle, 2021). For example, in a cohort of individuals with breast cancer, Manne (1998) found that stress experienced by an individual within a relationship, resulted in increased stress for their partner. Similarly, Kim et al. (2008) and Morgan et al. (2011), found that psychological distress experienced by one member of a relationship, impacted upon the QOL of both partners, within couples where on individual had breast cancer.

1.3.2.2. Relationship quality and intimacy:

Relationship quality may be of more importance than relationship status when considering the impact on wellbeing (Mcpheters & Sanderg 2010; Murray et al 2020). Romantic relationship quality and satisfaction was positively correlated with physical and psychological functioning within individuals living with multiple sclerosis or cancer (McPheters & Sandberg, 2010; Shrout et al, 2020). Young people with cancer, who reported low levels of conflict, and high levels of emotional support and communication within their romantic relationships, were found to be associated with better cancer management (Robertson et al.,

2016). Research also found that partner support is predictive of reduced negative emotional and cognitive impacts for individuals with chronic pain (Taylor et al., 2013). Stewart & Brindle (2021) found that partners are most valued by individuals with cancer, when providing emotional, informational, and practical support and involvement. However, Seiffge-Krenke (1997) found increased support was associated with higher levels of distress within individuals with diabetes, suggesting that higher levels of investment from romantic partners may be more taxing for some individuals. This may be specific to diabetes, given that general support is less helpful and necessary for managing the condition (Helegson et al., 2015). High levels of support within romantic relationships have also been found to pose other challenges for individuals with chronic health conditions; specifically, individuals can experience tension between their partner's dual roles of 'lover' and 'caregiver'. For example, individuals with cancer have expressed worries bout being vulnerable and dependent on their romantic partners, leading to feelings of being being a burden, and no longer loved (Rowe, 2018). Taleporos (2001) suggests that dependence can restrict opportunities to express sexuality, due to the lack of privacy. This may also create conflict, due to the impact on the balance of power within the relationship.

Jordan et al. (2021) found that young people with health conditions felt their condition affected their ability to enjoy a satisfying intimate and sexual relationship. Body confidence, sense of self, and self-esteem, were all found to influence individuals' perceptions of romantic and sexual relationships

For cancer patients, side effects of the illness and treatment, such as reduced sexual libido, exacerbated difficulties with intimacy (Rowe, 2018), with individuals also reporting challenges with regard to communicating sexual difficulties to their partners (Rowe, 2018). Erdogan & Karakas (2019), and Mushtaq & Ali (2019), found that lower levels of relationship intimacy increased emotional distress and reduced marital satisfaction for cancer patients. In line with this, widespread literature on disability suggests that societal attitudes may also contribute to intimacy difficulties and reduced sexual self-esteem, given the 'stereotypical' perception of individuals with physical disabilities as less sexual than able-bodied peers (Hunt et al., 2017; Hunt et al., 2018; Care Alliance Ireland, 2017). Individuals with chronic illnesses may experience similar

difficulties and stereotypes, perhaps due to the impact of illness on sexual performance and their ability to participate within ‘normative’ sexual activities.

Fewer problems and increased satisfaction within romantic relationships has been reported in relationships beginning after the onset of chronic illness; this suggests that the timing of illness onset may impact upon how readily a couple adjusts to disease-related role changes (Crewe et al., 1979; Crewe & Krause, 1988; Simmons & Ball, 1984). Alternatively, some research has found that relationship satisfaction and sexual adjustment was not related to the onset of disability, instead, correlating positively with individuals’ age (Kreuter et al., 1994). Concerns and challenges within relationships may also be gender-dependent. Men with cancer have been found to avoid being cared for within their romantic relationships, with importance placed on retaining independence (Rowe, 2018). As a result, men were less likely to seek support and talk about emotional difficulties within their relationships in comparison to women (Rowe, 2018), comforted instead by increased knowledge about their condition and ‘tangible facts’. Indeed, partner support has been found to be associated with greater frustration, worry, and sadness amongst older men with disabilities (Carr et al., 2017). Consequently, men have been found to be less likely to describe their partners as ‘carers’; in contrast, women with cancer talked about their male partners taking a ‘carer’ role (Rowe, 2018). In relation to being cared for, women reported feelings of guilt, embarrassment and demoralisation, experiencing this change of role as a loss of ‘feminine mystery’ (Rowe, 2018). Normative gendered discourses of men needing to appear ‘strong’, ‘independent’ and ‘masculine’, and women needing to be seen as ‘feminine’ may contribute to the sense of threat associated with being cared for by a romantic partner (Allen et al., 2014; Coyne et al., 1988; Galdas et al., 2005; Gerschick & Miller, 1995).

Gender-identity may also impact upon the significance of distress experienced in relation to sexual functioning. Whilst women with cancer feared that their partners would perceive them differently, men feared that their partners may not enjoy sex due to sexual functioning difficulties associated with their condition (Rowe, 2018). Similarly, Hunt et al. (2018), found that men experienced decreased self-esteem as a result of the physical limitations encountered within sexual relationships, due to the sense of achievement associated with sexual

performance. This suggests that traditional gendered discourses may impact upon sexual self-esteem, with men viewed as being ‘responsible for sexual pleasure’ and women viewed as ‘passive recipients to male gazes’ (Mulvey, 1989). Health-related symptoms such as fatigue, nausea, wheelchair dependency, and erectile difficulties may also be seen to challenge social norms of male sexuality and performance (Sakellariou, 2006).

These aforementioned concerns may lead individuals to avoid romantic relationships altogether, depriving them of the benefits that romantic relationships bring, such as increased support and intimacy (Carpentier et al., 2011; Hamilton & Zebrack, 2011). Seiffge-Krenke (1997) found that individuals without Type 1 diabetes, were more likely to develop romantic relationships sooner in adolescent and adult life, in comparison to those with Type 1 diabetes; once developed, those without diabetes were also observed to experience closer romantic relationships. In the current context of Covid-19, where individuals with health conditions are shielding due to high vulnerability, opportunities for finding and maintaining romantic relationships may be increasingly limited. In contrast, Maslow et al. (2011) found that emerging adults with childhood-onset chronic illnesses were just as likely as their non-ill counterparts to get married, have children, and have high levels of relationship satisfaction. Research has also shown positive changes within romantic relationships due to one’s health condition, such as the positive impacts of adapting intimacy to be about ‘more than just sex’ (Robinson et al, 2014). Intimate relationships can also be experienced as a ‘safe space’ from discrimination and oppression experienced within wider society, providing a means to challenge ableist discourses and promote sexuality (Hunt et al., 2018; Lee & Fenge, 2016; Liddiard, 2014).

1.3.2.3. Disclosure and Reproductive Decisions:

Disclosing health conditions within romantic relationships is another important factor for consideration, particularly when health conditions are invisible and/or have a hereditary component. For example, cancer patients found that disclosing their condition was particularly important, yet challenging, due to compromised fertility and uncertainty around prognosis impacting upon the future and development of romantic relationships (Rowe, 2018; Thompson et al., 2013). The importance of disclosure and associated fears have also been

expressed by individuals with other conditions such as cystic fibrosis (Sanderson, 2020) and SCD. The importance of disclosing one's condition connects closely with reproductive decision-making processes. For genetic conditions, there is the possibility of passing the condition onto one's biological children, impacting upon romantic relationships where having children is perceived to be a part of the relationships future. Research has found that reproductive decision-making is difficult for couples where one, or both partners, have a genetic health condition, having to decide if, and how, to pursue having a child. Although most couples show a preference towards options which allow the child to be genetically related to both parents, considering alternatives such as adoption, fostering, or using donor gametes, has been shown to increase stress associated with reproductive decision-making (Severijns et al., 2021). Gender differences have also been reported; Retznik et al. (2017) found that women perceived the process to be more difficult, required more information and had a greater influence on the final decision. This is likely due to women needing to physically carry the pregnancy and experience any associated medical treatments. Whilst men were not found to have a final say in reproductive decision, they were found to take more of a lead in consultations with HCPs, for example, asking more questions within genetic counseling appointments (Retznik et al., 2017).

The implications on reproductive decisions of particular health conditions means that disclosing health status to romantic partners may be especially important. Jordan et al. (2021) found that young individuals felt worried, reluctant, or inhibited when thinking about disclosing their condition and communicating its effects to romantic partners. Reasons for this included fear of rejection, protecting loved ones from the reality of their condition, stigma, and fears of being viewed as 'different', 'pitied', 'contagious' or 'unattractive' by their partners (Jordan et al., 2021; Rowe, 2018; Kaushansky et al., 2017; Thompson et al., 2013). Other reasons impacting disclosure included not wanting to be a burden, not wanting to pass on the hereditary disease to children, possible infertility, and in some cases, possible risk of premature death (Rowe, 2018). Research has shown that responses from historical partners, such as limited interest and willingness to discuss an individual's health condition, also impacts upon attitudes towards future disclosures. Notably, age was seen to mediate

this, with older individuals more likely to take an interest (Rowe, 2018). Concerns around when and how to disclose a health condition are common amongst individuals with health conditions when dating (Heller et al., 2016; Rowe, 2018); however, in conditions with an unpredictable nature, such as Cystic Fibrosis and SCD, participants described that increased and sudden severity of their condition meant that they often had to disclose their health status quickly to their partners, regardless of whether they had originally intended to or not (Broekema & Weber, 2017). Despite fears associated with disclosure, research has shown that disclosures can lead to increased confidence and self-esteem in oneself and within romantic relationships, as well as improved support (Heller et al., 2016; Kaushansky et al., 2017).

1.4. Summary and next steps

To summarise, the current literature suggests that SCD poses significant physical and psychological challenges, with those diagnosed additionally facing pervasive stigma, negative stereotyping, and racism. Individuals with SCD face complex challenges in relation to managing their health condition and maintaining their individual identity within education, employment, and their professional and personal relationships. Individual's relationships have been shown to provide significant social support, buffering against the more detrimental effects of the condition. Romantic relationships may be an especially importance source of support, and early adulthood is a crucial stage for developing romantic and sexual relationships. However, romantic relationships, when diagnosed with a chronic illness, pose unique challenges, despite their potential benefits. Therefore, it is important to explore the extent of current research on the experience of romantic relationships for individuals with SCD. In order to do this, a scoping review was conducted.

1.5. Scoping Review of Romantic Relationships in SCD

1.5.1. Search Strategy

A brief search was performed within 2 databases to identify and determine the relevant search terms required for the review. To identify published literature on romantic relationships and SCD, five databases were subsequently searched: PsychInfo, CINAHL plus, Scopus, Academic Search Complete, and Pubmed. Boolean phrases were used in conjunction with search terms, such as "Sickle

Cell Disease", "Sickle Cell Anaemia" and "romantic relationships" to identify relevant literature. The complete search terms used can be viewed in Appendix 1. Reference lists and citations of relevant identified papers were also searched to identify any other relevant research. All databases were searched from their start date until 2021.

1.5.2. Inclusion / Exclusion Criteria

Due to limited resources, only papers in English were included. All studies were required to recruit participants with SCD; therefore, studies which recruited solely participants with Sickle Cell Trait (SCT), or carers, or partners, were excluded. Studies were only included if the central research aim was about SCD and romantic relationships, or aspects of romantic relationships. No studies were excluded based on the country the research was carried out within or based on its research methods. Review papers were also included.

1.5.3. Results of the Scoping Review

In total, the search resulted in 889 articles across the five databases. After screening the titles and abstracts, 24 papers were identified of interest, excluding 865 articles. Reasons for exclusion included focusing on the biology and medical nature of SCD, or focusing on individuals with SCT or partner perspectives. After excluding duplicates, 6 relevant papers remained. After reviewing the full-texts, all six articles were found to meet inclusion criteria. Appendix 2 shows the PRISMA flow diagram; Moher et al. (2009), which outlines the search process.

The final six papers were focused on aspects of romantic relationships within SCD, such as, sexuality (*n*=1), reproductive decisions and genetic counselling (*n*= 4), and disclosures regarding the condition (*n*=1). However, no papers were found which considered or explored romantic relationships in their entirety. In addition to the six papers, one paper was identified through manually searching the included articles' references and citations. Access to the full research paper was however not possible, with the unpublished Master's Dissertation summarised on a SCD-specific website. Due to its relevance, the paper's findings are summarised alongside the findings of the included six papers, grouped according to their main focus. Appendix 3 shows a summary of the

demographics, aims, and methodological design of the papers included in the scoping review.

SCD and sexual relationships

Cobo et al., (2013) found that individuals with SCD and SCT lacked knowledge about pregnancy risks, priapism, and potential inheritance of the condition to their children. Half of participants had received genetic counselling. Despite finding that individuals with SCD experienced similar sexual development and relationships to those without SCD, participants and their partners were found to compare their relationships sexual characteristics and performances to individuals without the condition, resulting in discrimination and insecurity. Participants' first experience of sexual intercourse occurred mostly between the ages of 15 and 20 years, with most individuals reporting a current, active sex life. Most participants reported having 'satisfactory' sexual activity, and half disclosed experiencing their sex life as 'excellent'. However, just over half of participants also reported their sex lives being adversely affected by SCD, due to its associated difficulties and painful crises.

Duffy, (n.d.) found that men with SCD reported experiencing sex-related difficulties such as delayed sexual development, priapism, erectile problems, prolonged detumescence times, reduced fertility, and motility problems. The main issues that emerged from the study included restrictions on partner choice, due to the hereditary nature of SCD, and restrictions on sexual activity, due to having to account for and plan around disease-related complications and pain. Painful erections were reported during sexual activity, as well as other physical complications, such as arthritis and leg ulcers. Another theme that emerged was monitoring of oneself, others, and the condition, which was described as detracting from the pursuit and enjoyment of sexual situations. A loss of control of one's own body and increased dependency on others also emerged as a central theme, leading to issues around self-image, perceived masculinity, and male role expectations. Disclosure of SCD-status was also reflected on by participants, noted as a 'make-or-break' point within some relationships. Difficulties around whether and how to disclose SCD to partners was also discussed. The final theme found by the author, was a lack of information around the sexual and relationship aspects of SCD. However, as

the full paper could not be retrieved due to it being unpublished, the results reported should be interpreted with caution.

SCD and Reproductive Decisions

Gallo et al., (2010) found five central themes when exploring SCD and reproductive decisions: difficulties associated with pain episodes, difficult pregnancies, fear of early death, SCD's heritable nature, and partner choice. Partner choice included the importance of choosing a partner without SCD or SCT, to prevent having a child with SCD. Concerns were reported around younger individuals lacking knowledge and understanding around the hereditary nature of SCD, leading to concerns about partner choice. Reproductive options also arose as a theme, whereby some women exhibited the desire to have biological children, despite the risk of inheritance; in contrast, others did not want to risk passing SCD or the sickle cell trait (SCT) to their children. Some participants discussed the importance of prenatal testing to determine if their child would have the condition, and stated that this would be helpful in order to "psychologically prepare" them. Participants reflected on difficult decisions concerning terminating pregnancies if it appeared that their child would have SCD, due to their religious and personal beliefs. Participants demonstrated a range of knowledge and acceptance of different reproductive options, including birth control and tubal ligation. However, all participants were unaware of IVF (in vitro fertilisation) with PGD (preimplantation genetic diagnosis) as a reproductive option. Disclosing SCD-status with a partner also emerged as important for participants, with special consideration given to the timing of disclosure; a preference was shown disclosing SCD when relationships became serious or intimate, before any possible pregnancy. Disclosing was seen as a two-way process, suggesting the importance of finding out a partner's SCD-status too. Although early disclosure was not preferred, it was what participants felt they had to do, in order to avoid surprises such as frightening partners with unexpected SCD pain episodes. Furthermore, disclosing early was seen to contribute to conversations around continuing the relationship, having children, and considering reproductive options. Age was perceived to mediate difficulties around disclosing; participants felt that older and more mature they and their partners were, the easier it was to disclose. Reasons for non-disclosure included fear of rejection, being teased, and being treated differently.

Smith & Aguirre (2012) found that participants reported a lack of awareness and education amongst HCPs about reproductive decision-making for individuals with SCD and SCT. This was also found amongst individuals with SCT, who were unaware of the reproductive implications of having SCT. Authors also found that some females spoke of their male partners as denying having SCT, or being reluctant to get tested. Rationales for learning a partners SCT-status prior to commencing a relationship was also discussed, in order to prevent passing on SCD to future children. However, some individuals valued and prioritised the quality of relationships over and above the risk of passing on the condition to their children. Some women feared causing difficulties within their relationships if they were to ask about their partner's SCT-status; however the consequences of not asking about a partner's SCT-status were also thought about. With regard to having a partner with SCT, women discussed the importance of choices around prenatal diagnosis (PND), in order to have options and time to prepare for having a child with SCD. Reasons against PND included the fear of a miscarriage, difficult decision-making regarding abortion, and PND's being offered too late by HCPs.

Rance & Skirton (2019) found that participants reported receiving education from HCPs about the causes of SCD and its social and health implications, such as potential infertility. Knowledge about transmission of the condition was varied and often incorrect, despite participants awareness of SCD's heritable nature. Pregnancy decision-making was influenced by participants' attitude towards SCD, their beliefs about their ability to manage their child's SCD, and the level of risk of their child inheriting the condition. Participants varied in their views of whether they wanted a child, due to the risk of future children inheriting SCD. Knowing their partner's health status was also found to be important. This review also found that most participants supported premarital screening to determine partners' sickle-cell status, however, they felt that the responsibility often fell to female partners to instigate investigations, with some partners refusing to engage in prenatal testing. This review also found that some participants were in support of PND, for instance, due to personal negative experiences of SCD, economic stress, and concerns for their child's QOL. However, most participants did not support PND, due to and religious and

ethical reasons. The emotional and psychological impact of reproductive decision-making was found to be substantial.

Ross (2015) found that women with SCD had different motivations for asking their partners to undergo genetic testing. Some participants described wanting to prevent physical suffering for their future children, due to the pain they've suffered themselves. Others discussed wanting to prevent personal feelings of guilt for having passed on SCD to their child, as observed within their own parents. Preventing their children from experiencing illness-related stigma was also listed as a reason for undergoing genetic testing, again, due to personal experiences of stigma within the healthcare system. Other motivations included determining whether or not to enter into or continue in an intimate relationship. Some participants additionally expressed that their motivation stemmed from their parents' decision to not undergo genetic testing before giving birth to them. Women in this study did not express any difficulties around disclosing their status to partners. Notably, participants within this study who asked their partners to complete genetic testing were older in age, perhaps protecting against some of the difficulties experienced by younger adults with SCD

SCD and disclosure to a romantic partner

Derlega et al. (2014) found that individuals were more likely to talk about their thoughts and feelings regarding SCD-related pain to God and medical providers, as opposed to parents, siblings, or intimate partner's. Talking to God and parents was associated with better psychological adjustment on some measures. Talking to siblings, intimate partner's, and medical providers was also related to willingness to seek support from a physician with future pain episodes. Furthermore, authors found that talking about their pain was considered by participants to be a helpful strategy for managing SCD.

1.5.4. Conclusions

The current research base highlights the significance of reproductive decision-making, SCD disclosure, and sex-related consequences of SCD. The scoping review found that amongst those with SCD and SCT, there is a lack of knowledge about reproductive implications of SCD. Difficulties were found around reproductive decisions, with the tension between restrictions on partner

choice and hopes for biological children without SCD, discussed. Participants additionally expressed dilemmas surrounding PND, given its difficult nature and decisions around terminating or continuing pregnancy if a child has inherited SCD. The importance of a two-way disclosure was discussed, with sharing one's own SCD-status and finding out about a partner's SCD-status, both considered essential within serious relationships before pregnancy. Nevertheless, some individuals expressed prioritising the quality of romantic relationships over and above their partner's SCD-status. The scoping review additionally suggested that SCD influences the sexual relationships of individuals with SCD, for instance, limiting sexual activity and causing erectile problems. Concerns around delayed sexual development and reduced fertility also emerged, connecting to individuals' self-image, perceived masculinity, and gender-based role expectations.

However, the themes and issues identified within the research were explored in isolation, as opposed to within the context of a romantic relationship. Furthermore, most of the studies found within the scoping review were conducted outside of the UK, in countries such as Jamaica, Brazil, and the USA, whereby different cultural values and practices may be experienced, as well as a different healthcare systems. Therefore, understanding how these issues operate within the UK context is important. Additionally, the included studies did not focus solely on SCD, but included individuals with SCT, who may have different experiences due to their lower symptom severity. The scoping review also included both women and men, which literature has shown may have different experiences of living with SCD. Overall, the small number of papers found highlights the lack of research within this area.

1.6. Rationale and aims for Current study

In conclusion, research into the impact of SCD on romantic relationships within the UK is scarce. Research exploring the effects of chronic illness more widely suggests that living with a health condition impacts significantly on the perceptions of and experiences within romantic relationships; relationship formation and maintenance, sexual relationships, and hopes for future relationships can also be impacted by an individual's health condition. The scoping review highlighted aspects of romantic relationships which are of particular significance within the SCD population, including reproductive

choices, sexuality, and disclosure. However, there is a current lack of research within the UK, and within male populations, in comparison to female populations; despite SCD not appearing anymore prevalent in females than males (Cobo et al., 2013). Considering the gender differences identified, and the specific effects of SCD on men, it is important to explore male experiences of romantic relationships specifically. Many papers have identified that intimate and more committed long-term relationships emerge within young adulthood (Kansky & Allen, 2018), with individuals beginning to think about marriage and children. Therefore, participants within early adulthood would be the best placed to participate within research exploring this topic.

Whilst research has shown that reproductive decision-making, sexual intimacy, and feelings towards disclosure of health status are all impacted by SCD, research is yet to explore holistically the impact of SCD on romantic relationships, with young men with SCD living in the UK. The current research project will therefore be the first study to explore, in its entirety, the effects of SCD experienced by young men on their romantic relationships.

1.6.1. Research Question

How does SCD impact on young men's romantic relationships?

2. METHODS

2.1. Epistemological Position

Research processes are often guided by underpinning assumptions and beliefs (Hays & Wood, 2011; Madill et al., 2000). These are communicated through research taking an epistemological position (Crotty, 1998). Epistemology concerns how one can arrive at certain knowledge or truth, and therefore what counts as knowledge, how knowledge is gained (Willig, 2008) and how much research findings can reflect reality (Harper, 2012). The epistemological stance therefore highlights the relationship between the 'reality' I explore, as the researcher, and the influence of this on the research processes chosen.

There are two key epistemological positions. Realism suggests there is only one objective and measurable known 'truth' and 'reality' behind a phenomenon, which is open to explore, but separate from one's own beliefs and understanding (O'Reilly & Kiyimba, 2015; Ponterotto, 2005). The other is relativism / social constructionism, suggesting that the 'truth' of a phenomenon is constructed within the context of culture, history and language, and therefore there are multiple, equally valid 'truths' of a same phenomenon, depending on different contexts, and how one understands it (Burr, 2003).

Qualitative research usually encompasses a critical realist position, lying in-between realism and social constructionist positions (Ponterotto, 2005). Critical realism suggests there is a 'truth' that may be based on theories and research; Danermark et al. (2002), however how we know this, also depends on one's cultural and contextual position (Willig, 2012). For instance, critical realism allows for SCD, a health condition, to be seen as a reality existing, whilst also acknowledging how individuals experience, understand, and make sense of SCD, depends on the social, cultural, economical, and political context from which they speak, i.e. their gender and race identity, discourses of illness and health, and relationships. Therefore the truth is seen in a subjective way depending on individuals own experiences and beliefs, and can change over time (Bhaskar, 1978; Bunge, 1993; Finaly, 2006). It must be acknowledged that my own views and experiences will also impact analysis, and thus outcome of the data, whilst finding understanding and truth of what is happening in the

research through the participants' words (Willig, 2001).

2.2. Qualitative Research

Qualitative research aims to answer questions such as 'what' is going on, and 'how' (Green & Thorogood, 2010), which is particularly relevant where there is a lack of existing research or an area. The knowledge of how SCD affects romantic relationships for young men cannot be objective and the research aims do not suggest proving theory. Instead, they hope to explore and find meaning and understanding of participants' idiosyncratic and subjective experiences, which qualitative methods is fitting for, through its open-ended nature (Denzin & Linton, 2005; Smith, 2008; Willig, 2013).

2.2.1. Rationale for choosing the Approach to Qualitative Analysis

Interpretative analysis looks at research through contexts beyond the text, incorporating theoretical understanding, and drawing upon socio-political and cultural contexts for further understanding. For instance, considering gendered discourses, when investigating why a man with SCD may have a certain perspective. Different approaches using interpretative analysis were considered.

Interpretive Phenomological Analysis (IPA); Smith et al. (2009), focuses on individuals' subjective meaning making of their experiences, and their views of the world. However IPA's phenomenological epistemological stance is different from the critical realist stance and is concerned with phenomenological understanding of lived experience, taking individuals experiences as they are, lacking consideration of pre-determined theories, and wider contexts (Willig, 2012). Grounded theory; Charmaz (2006), incorporates individuals' experiences as driven by social and cultural phenomena, however focuses on these processes to create new theory. Discourse Analysis; Potter & Wetherell (1987) focuses on language used and how this constructs an individuals social reality, for instance looking at socially patterned meanings when an experience is spoken about (Willig, 2008).

Thematic Analysis (TA); Braun & Clarke (2006;2021), fits with the critical realist epistemological stance, focusing on understanding and interpreting individuals' experiences through identifying, analysing and reporting patterns within data. It

authorises both a social and psychological interpretation of data, and is widely used in qualitative data analysis. Thus TA is deemed the most suitable/appropriate analysis for this research. Joffe & Yardley (2004) suggest that TA allows for identification of a particular group's conceptualisation of a certain phenomenon, which is relevant for this niche, new area of research.

2.3. Ethical Considerations

2.3.1. Ethics Approval

All research procedures adhered to British Psychological Society Code of Ethics and Conduct principles (BPS, 2018), and ethical approval was granted for the research by the University of East London's School of Psychology Research and Ethics Committee in early June 2020 (Appendix 4), and amended in late June 2020, at which point data collection began.

2.3.2. Participant information Sheet

A participant information sheet (Appendix 5) was provided explaining research aims, why the research was being carried out, what the research would entail, and how the participants' information would be used, stored, and disseminated. Participants were informed how confidentiality and their anonymity will be maintained, and of their right to withdraw from the research.

2.3.3. Screening Call, Consent, and Debrief

Participants were offered a screening call to confirm they are eligible, make sure they have a safe and private space to interview from, and an opportunity to ask any questions. A consent form (Appendix 6) was provided prior to the interview, and a debrief form (Appendix 7) provided within 24 hours after the interview, as well as a reminder of their right to withdraw.

2.4. Research Methods and Design

2.4.1. Inclusion Criteria

Participants had to be of male sex, aged 18-30, to capture early adulthood whereby serious romantic relationships may be forming or have recently been formed, with a diagnosis of SCD, and currently living in the United Kingdom

(UK). This was in order to have some form of shared culture. Participants were only eligible if they spoke English, as interpreters introduce issues around confidentiality and anonymity, and translating between languages may present difficulties. Eligible participants could be of any 'relationship status' and identify with any sexual orientation.

2.4.2. Recruitment

I consulted with a SCD Special Interest Group (SIG), to gain advice on recruitment and wording for the interview schedule, and recruitment poster. Following the meeting, a recruitment poster (Appendix 8) was designed and shared on social media, such as Twitter and Instagram to recruit participants. The research poster was also sent out to UK SCD charities via email, and discussed over the telephone. Individuals in my own network, and wider networks were also made aware of the study through Whatsapp, and through sharing the research poster to their own informal personal networks, as well as by word of mouth. Recruitment also took place through asking participants to inform others they knew with SCD, about the research, who may be interested in participating, utilising a snowballing process (Faugier & Sargeant, 1997). Those that expressed interest in participating were sent the participant information sheet via email, followed by a screening call, and then sent a consent form. Participants were given time in between these stages in order to allow them to thoroughly consider whether they wanted to participate and prevent any type of coercion. If participants did not respond to emails or Instagram messages, this was respected as their choice to not respond or be involved with the research, and no more than one follow-up email / Instagram message was sent.

2.4.3. Challenges around recruitment

The population to be recruited, was already a very small population to come forward for research; young men with SCD. Recruiting from this pool, to talk about a topic that is deemed very personal and intimate, further limited the recruitment pool. Due to the Covid-19 pandemic, recruitment could only take place remotely, further limiting methods of recruitment. Additionally, the population I was recruiting, came under the 'shielding and vulnerable' category for Covid-19. Despite research taking place remotely, 'shielding' may have affected this populations wellbeing and mental health, due to self-isolating for

months, but also due to other difficulties they may have encountered such as being furloughed, or made redundant, effecting their motivation for wanting to take part within research. Nevertheless, these challenges were addressed through active recruitment, messaging people directly through Instagram, and increasing the eligibility criteria of ages, from 18-30 to 18-40 years-old. Through these efforts, an adequate number of participants were recruited.

2.4.4. Participants

Eleven men with SCD initially expressed interest on Instagram, from across the UK, ranging in ages 20-39 years. However four men declined to participate, so the final sample consisted of 7 men.

2.5. Data Collection

2.5.1. Demographics

Basic demographic information, to gain contextual information of the sample, is presented in Table 1. Only averages and ranges are provided to maintain anonymity.

Table 1. Participant demographics

Age	*Range*: 20-39 years old *Average*: 30 years old
SCD Genotype	SS (*n=6*), SC (*n=1*)
Ethnicity	Black British African (*n=4*), Black British Carribean (*n=2*), Black British N/A (*n=1*)
Location	UK (majority in London [*n=5*])
Currently in a relationship?	No (*n=5*), Yes (*n=2*)
Sexual Orientation	Heterosexual (*n=7*)
In Employment?	Yes (*n=5*), No (*n=2*), Student (*n=1*)
Number of pain crisis annually requiring hospitalisation (rough estimate)	Average: 3 times a year (*however most participants spoke about having more crisis per year when they were younger*)
Any other Long-term conditions?	No (*n=4*), Yes (*n=3* including strokes, blindness in one eye, chronic pain, and lung disease, all as a result from SCD).

2.5.2. Interview Guide

The interview guide (Appendix 9) was developed based on the literature review, which enabled me to identify issues that were likely to be relevant, in addition to conversations had with the SIG. Due to anticipated challenges with recruitment, men with SCD were not consulted as they would then not have been able to participate in the study.

The interview guide utilised a staged approach, starting with a broader, more general question to ease participants in, before asking more specific and focused questions. Questions were left open-ended for participants to respond in whichever way they felt comfortable and appropriate, and to not feel coerced into responding in a certain directed way (Hugh-Jones, 2010). The interview guide consisted of 7 questions to facilitate an otherwise broad topic, however these were used flexibly depending on participants' responses. Follow-up questions and prompts were also added to the interview guide to encourage

participants to expand on their responses, to allow for more useful data. (Leech, 2002; Ryan, Coughlan & Cronin, 2009;)

2.5.3. Interviews

A semi-structured interview was employed, utilising the interview schedule. Interviews are deemed to be useful in exploring individuals' understandings and perceptions of a selected topic, Braun & Clarke (2013), and a useful method for collecting data when using TA (Braun & Clarke, 2006). Semi-structured interviews were chosen as their flexible nature allows for an understanding into a phenomenon, through giving the participant the freedom to explore avenues they feel are personally relevant, and respond using their own words, and give their unique meaning (Willig, 2013). However, they are also structured enough to allow for feasible analysis, including a focused starting point, allowing the participant to tell a coherent story. Individual interviews were chosen to allow for greater disclosure of experiences, considering its sensitive and personal nature.

Due to this remote nature of the research, there was no risk to myself. My supervisor was also kept up to date regarding when interviews had taken place and provided me a space to debrief if needed. There was no anticipated physical or psychological risk of harm to participants either. However, I was aware of the sensitive topics that may have been elicited through re-telling experiences within the interview. To minimise this, participants were explicitly told about the topic of the interview in advance, and I consciously asked the participants preceding the interview how they would like the interview to be addressed should distress arise, and how I would best know. Participants were reminded that they could stop the interview and withdraw at any point, or take a break if needed. Participants also were not obliged to answer any question they felt uncomfortable to. I also took extra caution to be able to notice if a participant was feeling uncomfortable, and if so to change the question direction.

Seven interviews were conducted. Interviews lasted between 49 and 77 minutes. The interview started by allowing the participant to ask any questions if needed, followed by reminding participants they could take a break if required. Participants were reminded about their right to withdraw at any point, and that the interview would be recorded, with the reassurance that confidentiality and

anonymity will be maintained. Lastly, verbal consent was gained prior to commencing the interview.

The interview guide was modified slightly based on experiences in earlier interviews, including participant feedback and re-listening to previous interviews. Post-interview, participants were given a space to debrief, and give any reflections on how they found the interview. Participants were also asked whether they would like to be sent a summary of the findings once the research had been completed and written up.

2.5.4. Resources

Microsoft Teams Videocall was used to carry out the virtual interviews, and record them, as well as a dictaphone, for a back-up recording. The recording files were stored on a secure password-protected computer, within a password-protected file. An Instagram account was also created specifically for recruitment for the research. Participants contacted me via the Instagram account, and/or my university email address.

2.6 Data Analysis

2.6.1.Transcription

Interview recordings were manually transcribed verbatim, in order for the information to be 'true to its original nature', Braun & Clarke (2006), and as soon as possible after the interview was conducted. Basic punctuation was added to sentences when transcribing, to facilitate readability. Transcriptions were at semantic level, incorporating what was said, as opposed to also highlighting how things were said. Transcribing was carried out by myself, which also allowed for familiarisation with the data; the first phase of TA. Once each transcript was written, it was checked against its original interview recording, to ensure accuracy (Parker, 2005). All transcripts were anonmised, using unique participation numbers, and participant names replaced with Pseudonyms. Other identifying information was omitted from the transcripts and replaced with a general, brief description. These anonymised transcripts were stored on a password-protected file, within a password-protected computer, which only I had access to. A presentation key for presenting extracts of the data in the Results chapter, can be found in Appendix 10.

2.6.2. TA Procedure

Analysis was conducted in line with Braun & Clark's (2006;2021) guidelines, and took place in 6 phases. Although the six phases are stated below in an ordered and linear way, some stages we repeated and/or revisited to further support theme development within analysis.

Phase 1: Familiarisation with the transcript

As I conducted the interviews, the immersion process started here. Through transcribing, I further familiarised myself with the data. Each transcript was then 'actively', in a curious way, re-read, to further familiarise myself with the data. At this stage initial notes and reflections, including initial patterns and meanings elicited, were written in a table, alongside the transcript (Appendix 11a)

Phase 2: Coding

The transcripts were then re-read and individually analysed through 'complete' coding, which aimed to systematically, line-by-line, identify all data significant to the research aims, and label it by hand in the margin, to provide codes (Braun & Clarke, 2013) (Appendix 11b). Microsoft Excel was used to document codes and categorise them into relatable groupings. This is in order to later group related data via codes across all the data transcriptions (Appendix 11c). All codes were accompanied with relevant data extracts, identified by page and line number, (Appendix 11d), some of which were shared amongst different codes. Surrounding text was also documented in order to keep context and therefore support understanding of meaning later within the analysis process (Boyatzis, 1998; Braun & Clarke, 2006). Contradictions and interpreted 'anomaly's' were also coded. In order to minimise bias and assumptions, transcripts and codes were re-read after some time away, to ensure appropriate coding. 69 codes were initially created across all data transcripts, and 60 final codes were chosen after grouping similar ones together.

Phase 3: Searching for Themes

Codes were grouped through similarity into emerging potential themes across all transcripts via visual mind maps (Appendix 11e), which highlight patterns within the data set. The themes are important in eliciting significant aspects within the data set. Both semantic and latent level coding, Boyatzis (1998) was

employed to extract themes. Coding occurred as directly observed from the data and close to the participants' perceived meaning, whilst creating themes, emerged from more deeper meaning, with consideration of wider contexts (Joffe, 2012). Thus an inductive approach was used, open to any novel, emerging concepts solely data driven, however with acknowledgement of the existing theory and literature base. Where latent coding was achieved, it must be acknowledged, that this was tentatively, and as only one of many interpretations/readings of the data.

Four themes were originally produced from the dataset (Appendix 11f). Codes were repeatedly checked against the original extract to ensure accurate representation of raw data, and were relevant under the potential allocated theme. The emerging potential themes were then reviewed further and levelled/separated under broader themes and subthemes on Microsoft Excel (Appendix 11g). The codes under these were checked again against their raw data extracts to ensure they were relatable under the new broader theme or subtheme. Codes that did not fit into themes at this stage were categorised under an 'unknown' theme, for their importance to be reviewed again later.

Phase 4: Reviewing potential themes

The final themes emerged were checked against the related codes and raw data extracts to ensure internal homogeneity; that the codes were a 'good fit', related, made sense, and coherent with the theme. Themes were also checked against to ensure enough distinction between them; external heterogeneity (Patton, 1990). Adjustments and changes were made in this repeated process to ensure final themes were accurate and rich in data, providing significant information that reflects important parts of the data set in regards to the research aims. Therefore the final themes were assessed to ensure they were a 'good fit' for the entire data set. Links between themes were also then considered here.

Phase 5: Naming and Defining themes

At this stage, themes were refined, through each theme summarised with a detailed analysis to capture its unique essence and concepts, through data extracts. Theme descriptions were outlined as well as researcher interpretations

of the themes in response to research aims. Links between different themes were also analysed and outlined. At this stage, a coherent 'story' was beginning to unfold through each theme, developing a narrative within each theme, and across all themes and the entire data set, therefore responding to the research aim. The final part of analysis involved renaming themes as appropriate, to better represent and reflect participant experiences, and give the reader a better sense of what the theme incorporates. This stage produced the final thematic map (Appendix 11h).

Phase 6: Producing the Report

Analysis of the coherent narrative emerging within and across themes, coupled with raw data extracts (to allow readers to evaluate raw data against analysis and the story drawn) is outlined, to provide a coherent analytic report, in the results and discussion chapters. A summary of the results will also be sent to participants.

2.7. Researcher Self-Reflexivity

When using qualitative methodology, research is partly influenced by interpretations unique to the researcher. Therefore reflexivity of these personal views and experiences, values and social identities that interact are fundamental (Willig, 2013; Yardley, 2008). This adds to credibility, rigour and validity of the research (Yardley, 2008).

As the researcher, I acknowledge the subjective positioning I take, Green & Thorogood (2010), and of my identities, values, and experiences, all of which would impact how I approach the research and interpret the data (Lyons & Coyle, 2016). For instance, these influence the chosen research topic, the epistemological positioning driving the research, the direction of the literature search, data collection and analytical process, and outcomes (Nightingale & Cromby, 1999; Parker, 2005; Runswick-Cole, 2011). To be transparent, I will outline my personal and professional positioning (Braun & Clarke, 2013).

I approached this research as a young, British-Indian female, with the privileged position of not having a chronic health-condition. Alongside visible differences

to participants, I also possess invisible differences (Burnham, 2008). Although research has suggested that men perceive females as more supportive, accepting and empathetic Myers (1989), the lack of shared experiences and identities i.e. gender, race, and health condition, may have prevented this perception, due to the lack of relatability. Furthermore, these differences may have led me to make certain assumptions, which may have driven the research. These assumptions may have subconsciously impacted on what participants felt comfortable to discuss or perhaps actively not discuss within the interviews, potentially due to power imbalances between myself and the participants (Willig, 2009). However, it could be argued that shared similarities such as age, and ethnic statuses, both of a 'minority' status within the UK, may have helped to build rapport and either enhanced, or minimised openness of disclosure of experiences (Bellamya et al., 2011).

I was also aware of potential concerns around opening up to discuss such intimate topics considering visible differences in identity between participants and myself, for instance, the gender difference of being a woman, and participants being men. This was addressed through using my clinical skills as a Trainee Clinical Psychologist. For instance, when approaching certain questions such as discussing intimate/sexual aspects of SCD and sensitive/shaming experiences, my manner was sensitive but straight-forward, to minimise embarrassment Bellamya et al. (2011), alongside responding in a normalising, sensitive and empathetic way. However I had to be conscious of my dual roles as a practicing therapist, and as a researcher. I endeavoured to reflect on how my questioning was influenced depending on which position I was taking, and let participants know my role throughout interviews as solely a researcher. I also considered how male participants may wonder about a woman's intentions to research men's views on relationships. I reflected that I have a strong interest and concern in social and health inequalities, specifically from previously working within an NHS SCD psychology service. Not only was I interested in bringing about awareness of a health condition which is under-researched, but also amplifying men's voices, and exploring their perspectives, as the limited research existing on SCD is based on womens perspectives. However, I was aware that this prior work experience may also have influenced and provided me with assumptions, as well as an invested professional interest in how

psychology can support individuals with SCD. Furthermore, my experience in systemic therapy training, and working systemically in practice, enhanced my knowledge and interest in the importance of relationships on psychological wellbeing.

To consciously reflect on these assumptions and how my position may affect the research, a reflective diary (Appendix 12) was written throughout the research process, as well as debriefs had, and reflections discussed with my research supervisor. Reflection is included throughout the report and further detailed in the discussion chapter.

3. RESULTS

3.1. Overview

Romantic relationships are not entirely distinct from other relationships an individual may experience for instance, informal relationships with family and friends, and formal relationships with HCP's and workplace employers. Interactions with these other types of relationships may inform thoughts, attitudes, and behaviour towards romantic relationships. Therefore when talking about romantic relationships, participants often referenced other relationships.

Three themes and seven subthemes were developed from data analysis and are shown in Table 2.

Table 2. Themes and subthemes

THEME	SUBTHEMES
1. Societal and Cultural 'norms' concerning romantic relationships	- 'Masculinity' - Missing out on 'normal' things
2. Lack of awareness and understanding, misconceptions and stigma around SCD	- Consequences of the lack of knowledge around SCD - Keeping SCD 'hidden' - SCD as more than just physical symptoms
3. Disclosing SCD within a romantic relationship	- Intention for disclosing SCD, and when and how this process is managed - Processing and effects of disclosure on romantic partners and the relationship

3.2. Theme 1: Societal and Cultural 'norms' concerning romantic relationships

This theme is related to the expectations and pressures men with SCD feel they need to adhere to, partly due to societal and cultural norms of what a 'normal' romantic relationship should involve, including a man's stereotypical role within

it. Participants discussed how living with SCD makes it hard to abide to these 'norms'.

3.2.1. Subtheme 1: 'Masculinity'

All participants described what they felt their 'role as a man' in a romantic relationship should involve, including 'stereotypically masculine' qualities such as being the 'provider', appearing 'strong', and 'not talking about their feelings'. Whilst these were normative expectations, most participants also reflected these as their own preferences. Due to the debilitating nature of SCD, participants felt these normative expectations were harder to adhere to. However, these attitudes were discussed as evolving, rather than a fixed state, perhaps indicating that participants had to adjust their own preferences in light of the constraints imposed by SCD. This highlights a possible tension between their preferred ways of 'being a man' within a relationship, versus the reality of their situation.

James and Kofi speak about these 'stereotypically masculine' qualities, and describe these as an 'old school way' of thinking. Kofi spoke about the differences in this with women's 'stereotypical roles' and used examples of physical frailty and vulnerability to show how SCD impacts these 'stereotypically masculine' qualities.

> James: we're supposed to be the strong ones and providers(…)it might be an old school way of thinking, but that is my way of thinking(…)when you're not able to do certain things you do feel a bit inferior(...)supposed to be the man(…)its just unwritten rules or something (*laughs*)(…)But you cant be strong all the time(…)but that should be the aim.

> Kofi: chivalry, providing, all of those things that were the old school way(…)I'm that way by nature anyway, but I just think it's a bit cheeky for it to still be an expectation in this new school world where women are not housewives(…)I'll do it anyway(…)if a man isn't able to provide for the woman, you should just leave her alone(…) if a woman's gonna take care of home like be maternal and stuff a man should also be taking care of the home financially(…)*[how SCD affects this]* times when its like

> debilitated me to the point where I cant stand up in the shower(…)need to put me in a wheelchair to go here or to go there(…)I do feel it .

Dayo and Mike also voiced differing roles for men and women upheld by society. Dayo expressed how SCD interferes with upholding these gender roles, and instead exacerbates an illness identity, resulting in him feeling vulnerable. To minimise this, both speak about hiding their pain. Mike spoke about the pressure he puts on himself, displaying tension relating to these 'norms'. Mike associates some of these pressures with what he imagines women's expectations of men to be, and seems to compare himself unfavourably with other men who can provide these.

> Dayo: I probably would have been a bit more masculine(…)hobbies and you know being more of a lads lad(…)SCD has just pushed me back a little bit(…)some people just see me as a sick person or unable to do things or less of a man kind of thing(…)when I do get crisis I'm bed bound, cant go like to the toilet(…)probably when I'm like my most vulnerable (…)I kept it all in [*the pain*](…)I didn't want to seem weak or vulnerable around my ex(…)I saw a video of a girl who was going through a crisis and screaming(…)I could never put it out there to the world like that(…)girls with SCD seem a lot more open about it(…)whereas with the guys they tend to not speak up about it and not talk about it(…)definitely linked with masculinity.

> Mike: Maybe its more on the females when it comes to emotional, but when it comes to appearance and finance and providing and security and all of that, a man has to do that(…)I've gotta be the man I gotta like hide when im in pain(…)gotta keep it altogether. Keep strong. Because that's what they find attractive maybe, or that's what they need(…)You just gave me a mad thought in my head…wow…it's really bad I shouldn't do this to myself…not only do I have pressure on myself cause of SCD, I'm putting more pressure on myself because I'm a man in my society(…)battle in my brain(…)well now you're X age and you should be driving and then you should be doing this but you cant(…)some females, they have a tendency to be that my man has to have a car, a house, this,

> that(…)but its like the insecurities cause I don't have those things(…)is it cause I have SCD.

Some participants specifically addressed cultural expectations of what it means to 'be a man', and how SCD interrupts this.

> Dayo: African background(…)men are like the providers(…)supposed to do everything and support the family and be the head of the house(…)I probably might have questioned whether I could do it (*laughs*) um with SCD

> Isaac: The man is seen as the rock of the family. I've been brought up in a traditional Carribean household. My dad is the breadwinner

However some participants described these attitudes as evolving from perceived gender-based expectations, to more equal-roles, and a partnership.

> Kofi: I've just learned to accept it is what it is. When I'm on my feet I'm doing all of that so when I'm out of it take the wheel until my bounce comes back until my recovery(…)I know I would do the same like if you're out of it like I'm cooking I'm making sure house is clean, I'm doing the laundry

> Dayo: I appreciate working together and trying to build something rather than its just all on my shoulders kind of thing(…)it just changes overtime

3.2.2. Subtheme 2: missing out on 'normal' things

Participants spoke about SCD and its unpredictability resulting in missing out on 'normal' activities, within romantic relationships, and discussed how the Covid-19 pandemic impacted this. However, some participants stated that they try to participate in 'normal' activities regardless of how SCD may restrict them.

Some participants expressed SCD disrupting romantic 'date' activities and having to cancel plans last minute. The effect of this both on themselves and their partners was discussed. Alongside making planning difficult, Isaac

mentioned his ‘normal’ developmental experiences being disrupted and derailed due to managing SCD, leaving a residue of uncertainty. Mike shares this uncertainty, discussing a fantasy of what life may have been like without SCD.

> Femi: I might not feel strong enough to run down the park with you or maybe days where I don’t go out in the cold and go watch movies(…)definitely affects the relationship(…)especially when you want to do a lot more than just stay at home(…)stay in the bed and receive blood transfusions. You want to do a lot more but you cant cause look at your circumstances(…)I would like to impress the lady, would like to do stuff for her(…)but my illness might prevent me.
>
> Mike: I want to travel to certain places(…)I want to go to Winter Wonderland(…)but I cant, that’s a damp on my spirit or my partners spirit(…)and you have to think and plan(…)without SCD my confidence would have been over the roof. I’ll be doing all different kinds of sports. I’d be driving(…)would have grown up differently(…)different abilities which come with different roles and different values, different perspectives and be able to travel the world, do different things. Play soccer, play basketball(…)my priorities be different
>
> Isaac: when I’m borderline on a crisis I wont do that extra thing(…)if I was to go out with friends or to organise a date(…)to cancel last minute because of how I feel has an effect because they think they’re just flaking on me, they don’t want to speak to me but that’s actually not the case(…)growing up with SCD I’ve probably missed out on a lot of normal things, going out(…)I was in and out of hospital so much when I was a teenager(…)probably would have had more girlfriends (*laughs*)(…) haven’t been able to get out there as much as everybody else

Participants discussed how the Covid-19 pandemic impacted on their romantic relationships.

> Femi: my guys out there with SCD on things like bumble(…)definitely affected a lot of things for them. You know, looking for a partner(…)you obviously can't meet up cause you're shielding

> Ade: not allowed to see anybody(…)even my partner was unable to see her(…)put a lot of strain and plus the fact that I contracted Covid(…)almost died with it(…)took me a while to get over that physically and mentally

Despite the pandemic and SCD restrictions, Dayo and Isaac spoke from a contrasting perspective.

> Dayo: I do try to, you know, like be as normal as possible and just do what I wanna do

> Isaac: [*in pandemic*] I actually went on holiday(…)you have to go out and live your life(…)I'm not going to let SCD be an excuse(…)others have broken barriers and they've inspired(…)even if I've got this condition and he can do it then I can definitely do it.

3.3. Theme 2: Lack of awareness and understanding, misconceptions and stigma around SCD

The second theme relates to the lack of awareness and understanding of SCD. Participants spoke about how this, as well as misconceptions around SCD including cultural stigma, results in 'hiding' their condition. Participants also expressed the lack of awareness from others, of other ways SCD impacts, aside from its physical consequences.

3.3.1. Subtheme 1: Consequences of the lack of knowledge around SCD

Participants described a lack of awareness and knowledge around SCD from the public, but also from HCP and romantic partners. Consequences of this included difficult relationships and incorrect medical treatment. There was also a lack of understanding around SCD from themselves, however this evolved with age; participants learning through self-experience, perhaps through

changing their relationship with the condition, to one more associated with acceptance and appreciation. Participants also discussed consequences from culturally specific stigmas they face.

Some participants indicated that although the general public, schools, and employers, have heard of the condition, they lack a deeper understanding.

> Kofi: when you meet people they'll often tell you 'yeah I've heard of that [*SCD*] my aunty has that'(…)they might hear 'so and so in hospital' but they haven't seen what its done or what its taken away from them(…)its just a word that they've heard of.

> Ade: students will have a SCD crisis in schools and have been expelled because they were reacting(…)treated as if they were problem students(…)nothing in place to cater for students who have SCD(…)people fail to acknowledge how my condition limits me(…)several employers refused to offer any sort of adjustments.

Participants also discussed how little HCP's knew about SCD management, resulting in poor and incorrect medical care, with significant consequences, including 'contemplating life'.

> Kofi: I was injected the wrong medication(…)left scarring in my lungs(…)[*another time*] they didn't know what to do because their haematologist was on leave(…)they started phoning around different hospitals, and they didn't know what it was [*priapism*](…)12 different doctors came(…)DRs taking out their phone to google it.

> Femi: I even had to explain to the GP [*what SCD is*]

> Dayo: got crisis in my leg [*somewhere in Europe*], they didn't understand I had SCD so gave me a cast on my leg, they thought it was fractured(…)[*somewhere else in Europe*]out late drinking and it was cold(…)one of my friends was like 'it was probably kidney stones'(…)when I went to hospital they thought I had alcohol

poisoning(…)people not being treated properly(…)in London they gave me paracetamol as my first analgesia and its like…I've got paracetamol at home, I was like…I cant, I cant with this, it was actually so bad that I was contemplating life

Participants also referred to themselves as lacking in understanding of SCD, perhaps due to not being educated by HCP, and instead having to learn overtime through self-experience and their own research.

Dayo: when I was younger I didn't know my triggers or anything like that(…)paediatrician would explain things and give me different medications, so that made me aware that I have the condition but it didn't really help with understanding what it was(…)experience comes with age, getting to understand how to manage SCD so now I'm a lot more aware(…)I do a lot of research(…)you have no clue about how to do it because there isn't like a textbook

Kofi: I've had that [*priapism*] so bad for years and the joke is I didn't know it was SCD because it wasn't actually told to me until I was in my early 20's(…)[*in his early teens:*]..in a changing room for football(…)one boy was saying he woke up with morning glory(…)I was like I had that last night too and I was crying and it hurt and everything(…)everyone turned around and looked like what you talking about(…)it was for hours hurting(…)I just thought it was growing pains or something

Participants voiced the lack of understanding within romantic relationships too, resulting in relationship challenges, or romantic relationships ending.

Isaac: [*had to cancel last min plans*] just one of those things that people might not understand and then you've given them the reason but they've just cut things off

Ade: was often teased about[*priapism*](…)but when I told her about the implications of you know having an erection that lasts so long could lead

to me being impotent, so I could basically damage down there, and other complications to(…)it was challenging because she just didn't realise why I would be so tired

Family and friends of participants who were aware of the condition, often had misconceptions and cultural-specific beliefs and stigma towards SCD.

Femi: in Africa they're not treating me equally because they think(…)if you touch him he might just faint, because they are not really aware what the actual sickness is.

Ade: I didn't even know I had it [*SCD*](…)I couldn't talk to my family due to the negative stigma(…)made me very resentful for myself for having it(…)in Nigerian culture there's always a stigma with SCD (…)you're cursed you did bad in your past life or God is punishing you, or if you have SCD lets pray for you for all these demons(…)it contributes to people not talking about it(…)and when we do its don't date that person, stay away from that person, lets stop the spread of SCD by not procreating, and its just a negative spin on SCD…never a case of lets support this person(…)people have refused or stop dating me once they find out I have SCD

Ade mentioned his own ideas of how to improve this lack of awareness and misconceptions.

Ade: bridging the gap between teachers and students(…)nationally there's nothing(…)no known program at schools(…)there's only so much you can do from reading a textbook(…)case studies on individual patient stories(…)having conversations with patient experiences(…)more advertising of SCD patients(…)simple leaflet in A&E(…)hospitals having a direct link to my profile so can smooth transition for patients in hospitals(…)support services within the community (…)protocol to automatically get access and help(…)outreach services, support groups interlink patients together(…)hire more qualified in these areas to support

> giving incentives for people to actually pursue these niche fields (…)making the conversation popular.

Femi also referred to racism contributing to this lack of awareness of the condition.

> Femi: we don't get a lot of recognition(…)we've all seen that if this condition affected every one…I think you know what I mean by everyone…It would be treated differently…we're treated differently

3.3.2. Subtheme 2: Keeping SCD 'hidden'

Due to this lack of awareness and understanding, in addition to the 'invisibility' of SCD, participants preferred to keep SCD 'hidden' and not openly talk about it. However, this evolved with age, moving towards a more open and almost activist perspective of talking about SCD.

Due to not wanting to be judged or pitied, and feeling isolated in their experiences, some participants expressed keeping their SCD hidden, and lying about symptoms.

> Dayo: I used to keep quiet about it cause no one really experienced what I was experiencing(…)I just be in pain and you know explaining it to your friends…I just got a tummy ache or my leg hurts(…)used to not tell people that I had a crisis(…)used to blog about it anonymously(…)I don't want anyone to know its associated with me(…)don't want to be judged or looked at differently

> James: we always say were alright even if were not(…)I've always kept it close to my chest(…)I'm definitely not going to go round telling everybody(…)I'm not telling you to try and gain sympathy or for you to pity me or anything like that(…)it's just a bit long…like everybody you meet you gotta keep going over the same stuff again like I feel that's a bit of a waste of energy and too much of my info to give you(…)certain people even will use it against you like oh he cant do that he's got SCD

> Femi: you could not disclose you have SCD for months or even years, you could take your medications in secret(…)but I just don't like talking about it(…)there are days where I'm feeling pain, I just keep it to myself

This also extended to wanting to hide SCD in romantic relationships.

> James: used to lie a lot about it(…)I just didn't want the pity thing(…)she would phone me whilst I'm in hospital and I'm trying to act like I'm not in hospital (*laughs*)(…)they'd hear the machine beeping in the background or the nurse will come and ask you questions…your whole show is kind of flopped

> Isaac: just one of those things that had an effect on the relationship where I probably wasn't as open to letting them in(…)because you don't really want people to see you at your worst(….)embarrassing(…)want to put your best foot forward especially if you're early on in a relationship(…)the realness of me not being able to get up and walk or them having to help me, go to the toilet(…)I don't really want them to see it because I don't wanna show signs of weakness(…)maybe they wont want to be with me

As well as perhaps helping them to hide their condition, participants such as Kofi, alluded to the invisibility of their symptoms, as contributing to the reason for the lack of awareness and understanding of SCD.

> Kofi: because I look normal and I do stuff and I'm active. People don't realise what is actually happening inside of my body(…)because I'm not in a wheelchair. I'm not on crutches, I don't have my arm in a cast so there's no visible sign that shows I have a disability

However participants described a shift towards opening up about SCD, and discussed what helps facilitate this.

Dayo: I got to university and then I began to speak about it more because…people kind of knew a little bit more(…)now I'm very open about having SCD but it took me a while to get to that place(…)because I want to change the perception(…)I've been fortunate enough to have more friends that have SCD because I've been speaking about it more(…)I used to tell people when I've left hospital instead of when I'm going in because I didn't not want anyone to worry but now I can just be open(…)this happened later in life…probably from my early 20s (…)now I introduce myself like my name is Dayo, and I have SCD (…)I'm now acknowledging that it is a part of me

Ade: I was suffering in silence I had to have a reality check(…)taken a lot of work on myself to realise that I do need to help myself to get better in order to be in a relationship with anybody else(…)I had a lot of pain and resentment to myself in regards to having SCD (…)not until I started realising what its here for(…)its now time for you to let all the anger go and use this to channel into passion to create platforms for other SCD warriors to speak and reach out and exchange information(…)I didn't know how to defend myself in regards to certain questions it was a case where I just didn't really wanna go there with you having to explain it when I didn't know much about it(…)I'm transparent about my condition and how it effects me now.

3.3.3. Subtheme 3: SCD as more than just physical symptoms

Participants spoke about the lack of awareness of other ways SCD impacts them, aside from its physical manifestations, which takes the foreground. For instance, participants discussed the effects of SCD on their mental and emotional wellbeing. They discussed what can be done to support with this, such as therapy, and the benefits of talking to other men with SCD.

For instance, participants spoke about non-physical effects of SCD, through emotional and mental aspects of SCD, the toll of being in constant pain, interference of SCD with relationships due to a lack of socialising, and how this all effects self-perception, with significant consequences such as suicidality.

James: people focus on the pain(…)but there wasn't enough research done into the after effects about how you feel always being in pain and not be able to do things and you're always in your house and you might not socialise as much(…)it's a lot to deal with(…)the mental aspect is just as important as the physical aspect(...)as much as SCD does cause pain and crisis it can cause a lot of other complications(…)affect your mood and how you feel about yourself(…)you cant just escape your mind

Mike: tiring, its just draining, mentally, physically, emotionally(…)SCD has affected my mind more than it has physically, which is crazy

Ade: I suffered from a bout of very bad mental health and I was also on the verge of being suicidal

Participants discussed what may help these other effects, or has helped in the past, including the importance of having a therapist that is educated on SCD, allowing romantic partners to join therapy, and talking about sexual difficulties in therapy. Participants also stressed the importance of speaking to other male "sicklers".

Femi: [*pain*] affects patients psychologically (…)so definitely should be a kind of service put in place(…)even sexual health(…)cause I believe there's so many of us who might be struggling with what were going to do when we get into a relationship and not knowing how we want to communicate openly with the opposite sex or with our partner about pains(…)about what we go through with SCD(…)probably younger men to prepare them before getting into a relationship(…)and pull out whatever is that they have been keeping inside that might affect their relationship (…)what they think about engaging in sex(…)but before anyone goes into that kind of service, they need to understand what SCD is…from our point of view…understand how this illness must have impacted men in every way emotionally, mentally, and even in relationships(…)If we get this support would be fantastic…because that way we know were building a healthy guy, healthy in all parts

James: having an outlet to openly discuss how you feel and how its affecting you(…)express it(…)its good because I'm lucky most of my friends have SCD so we can kind of do that for ourselves…they know exactly what you're feeling...so if you can talk to other sicklers or a counsellor (…)a support meeting where people sit down and talk about certain things that they're going through(…)it might be helpful if you and your partner both go to see the psychologist(…)your partners there listening so they can get a vibe of how you feel because sometimes its not easy to tell that to your partner but easier to tell a stranger certain things

Mike: how important it is for a young man to have a male role model sickler(…)I grew up around women(…)its hard for them to...didn't talk about it(…)just emotionally was all over the place

Despite these significant physical, social, and mental health difficulties of SCD, participants expressed becoming appreciative of the condition overtime.

James: I would never change it and not have it because going through what I've gone through made me the person I am(…)decent person now(…)SCD teaches you to be humble(…)when you need people you have to realise you have to act in a certain way

Isaac: I'm forever grateful for my life(…)because I've been back and forth so many times at deaths door…it gives me an optimism about things when things are good, I can appreciate simple things like being able to work, able to jump up and down, waking up every morning, able to go and get my own breakfast, go to the toilet, things that people might take for granted, given me an appreciation.

Femi: I'm kind of optimistic towards it and I just see it as a blessing more now(…)I start seeing it as a superpower(….)I kept that positivity(…)I have been privileged to survive to tell my story and spread awareness and help other people

3.4. Theme 3: Disclosing SCD within a romantic relationship

Despite wanting to generally 'hide' SCD, the third theme relates to the importance participants placed on disclosing their condition within romantic relationships. Participants also discussed the effects of disclosing on their partner, and on the romantic relationship itself.

3.4.1. Subtheme 1: Intention for disclosing SCD, and when and how this process is managed

Participants preferred to disclose early on to romantic partners, however some spoke about this evolving with age and previously being reluctant. James talks about 'his cover blown' suggesting almost seeing SCD as a separate identity he was trying to hide. There was a strong sense that eventual disclosure is a motivated/strategic decision, based on concerns for the welfare of their future children. This seemed to drive the decision of when and how to disclose.

Most participants expressed disclosing to their partner as early as possible in order for their partner to offer support, find out in a less 'shocking' way, and to avoid deceiving their partner.

> Ade: the more upfront you are about it [*SCD*] the better it is(…)if I do have a crisis infront of someone else I would like to know that they know how to handle the situation properly

> James: it will take me six months plus before I tell you I've got SCD because I feel like I need to know it might go somewhere(…)but sometimes if you get a crisis and then the person is with you like your cover's blown(…)but I've learned that's not really the best way because it's a big way to break it to somebody(…)f you have the conversation beforehand it makes it a little easier(…)you have to give people a bit of a heads up

> Kofi: I'm an open book so I'd explain it at the start, especially if its not just casual if its a serious relationship(…)I've always been that way because I

> feel that everyone should be able to walk into something knowing what they're walking into rather than catch feelings and then find out later…that's deception

The most common reason for disclosing early was to find out if their partner had SCD or SCT, in which case all but two participants stated they would not continue with the relationship, due to not wanting to risk their children inheriting SCD, and/or for this to cause relationship difficulties. Participants describe this as a difficult, complex, hurtful, and some, as an uncertain, decision. With some participants not being able to continue relationships solely due to their partner's SCD status.

> Isaac: important conversation to have because there are so many people living with SCT(…)I don't really want my child to experience that…it might be a selfish way or it might be a more loving way(…)because why would you restrict yourself to speak only to people that don't have SCT when you could find somebody that does but then you have the risk of having a child with them(…)I might even change my mind in the future

> Femi: I don't want a child to go through what I'm going through(…)maybe even not telling her or disclosing it and then you guys have a child and the child has SCD it will definitely impact the relationship because they know that this is going to be a struggle

> Dayo: in the past where I haven't mentioned it…we get feelings and find out later then it becomes sort of an issue(…)getting it out as early as possible makes it easier to walk away…not too much investment…but that's easier said than done(…)the other girl she said we can always adopt(…)the genetic side of things is like a extra filter(…)its still early days so its okay to walk away but at the same time they're really cool(…)there's a lot of strain on the relationship. I didn't know how to handle that so I would move a bit crazy and just end relationships(…)it was always one of my uncompromisables I wouldn't want to have child that has SCD(…)discussion we'd have regularly…pre genetic screening, IVF…just felt very heavy…a very important decision

> James: a lot of my friends we'd make good boyfriend or girlfriend material but because we've got SCD it's a no go…the kid would definitely have it so things like that you've got to think about(…)finding out people's blood types or genotype if they've got SCD is a big part of getting in a relationship(…)because as far as I'm concerned then that's a killer its over so you don't really wanna leave it too long…because at that point I can cut it off and it still hurts a bit but you can cut it off. But if you go a little too far and then feelings is proper there it makes it harder

Some participants spoke about ways to increase the awareness of identifying whether individuals have SCT, and therefore reducing the chance of individuals passing the condition onto their children.

> Dayo: doctor mentioned 'oh you're getting to an age where you may start thinking about family planning'(…)in hindsight that was a good introduction into thinking more about how it works with the trait(…)could be integrated so much better from school age …PSHE…sexual health stuff…would have been smoother…around teenage years

> Kofi: there is a lack of knowledge like a lot of people that have the trait don't know that they have the trait(…)the way the government have made it compulsory for school nurses to go roundup every year 10 and give the BCG injection, why are they not going round and doing blood tests to tell them what their genotype is, because by the time they found out its too late and that's how most of us are born(…)should be enforcing that people are told their genotypes…. so that way its in their head…on their file and they know before they get into anything

However two participants contrastingly addressed dating whomever they like without restricting themselves to non-SCT partners. Mike felt less strongly about this, and seemed unsure, compared to Ade who mentioned having a child with SCD, however being prepared for this.

Ade: I knew she [*romantic partner*] had trait(…)we knew there was a possible chance they [*child*] would have SCD(…)we had all the medical specialists all the tests set up so as soon as they were born they started treatment(…)just made sure we had everything in place(…)I'm already prepared now I have a wealth of experience, got children with SCD, my parent and siblings have SCD…I'm knowledgeable(…)I wouldn't advocate for anyone to not date anybody(…)the fact I have a child that doesn't have any adverse reactions to having SCD in general…not to say if I have another child that they may be the same but I'm well versed enough to know that I can handle it

Mike: I wouldn't see someone and then ask them have you got SCD, or has anyone in your family(…)but it is a wonder like ok is this a smart decision because no matter how much I like you is it smart because we need to eventually have a kid(…)because the type of pain that I go through I wouldn't want none of my kids to go through but for me to be in a position to say no I don't want to get to know you because you have SCD…takes a part of my heart, it makes me feel some type of way(…)I like to love everyone equally(…) its something I gotta think about

3.4.2. Subtheme 2: Processing and effects of disclosure on romantic partners and the relationship

Participants discussed the effect of having, and managing SCD, on their partners. They discussed how their partners' reaction to this, impacted on them, and the romantic relationship itself. Some participants described romantic partners showing great care and concern whereas others described partners finding it difficult to maintain the relationship. The desire to avoid being a burden was a topic also discussed.

Ade and Kofi spoke about partners being caring and supportive and the benefits of this. Kofi expressed a higher and more intense level of care and concern from his partner, describing her as a 'carer' and comparing this to the lower level of care he receives from friends.

Ade: she's been so understanding its been relatively easy(…)I'm thankful that I have a partner I'm able to talk to(…)it wasn't until I spoke to my partner that she was able to help me…you know a load shared is better…its just breathes a relief knowing that you can talk to someone(…)she's able to assist me like if I'm really tired, 'just stay in bed what do you need me to do? I can bring your laptop I can bring your stuff for you to just make yourself comfortable…hot water bottle' all these things, alleviate my pain

Kofi: I vaguely remember her asking me 'you alright, you alright'…I could see the concern in her face was genuine(…)if I was in deep sleep or in the shower or at work and she's ringing my phone and I don't answer she'll always assume the worst until I call her back. Because some things have happened when I'm alone like I've fallen down the stairs, I've had a stroke, I gotta call my own ambulance, I've fainted and blacked out…so she will automatically panic(…)sometimes I'll take long in the shower and if I don't sound like I'm singing or moving she will bang on it to hear me respond(…)these are reminders of what my potential reality is because I look normal and do normal stuff(…)the level of concern she shows is a lot higher than others…they check for me discreetly like 'you good bruv'(…)because obviously its her journey and if we gonna do this for real then when it hits the fan reality is she will have to be the carer…partner is a full time carer.

Participants also spoke about more difficult reactions experienced from partners when visually seeing a crisis, some of which cause the relationship to end. Other reasons for ending the relationship include not being able to 'handle' carer responsibilities, and not being able to participate in things that 'typically occur' within romantic relationships such as more sexual and intimate activities.

Kofi: they're cool with it because they see me working, they know I'm active(…)but then when something does eventually happen and then they see me out of it...that's when it visually hits them(…)that's when its gone left(…)been scared off(…)relationships that have ended(…)I had a stroke…it was a shock to her…then I had a second one(…)it was scary

for her…everything looked completely uncertain(…)I was like if you cant take it I get it(…)another one [*partner*] that left when things got bad was a nurse(…)it was like 'I do 12 hour shifts everyday at work I don't wanna come home to do this again for another 12 hours'(…)especially if it's someone that you care about it's very difficult to deal with

Isaac: its difficult because when you're in a relationship you expect the physical side of it and if I'm feeling tired or unwell then I cant really have sex because I know its going to trigger a crisis(…)so if they're not understanding then it can have an effect(…)they can be in a mood with you

Mike: when I'm in hospital I'm always reliant on someone. If the person isn't as strong as me, they'll get to a point like I cant do this nomore I don't wanna be coming to hospital everyday taking you food and seeing you.

These relationship dynamics, in addition to the pressures and expectations of 'masculine norms' within romantic relationships, may make participants feel like a 'burden' within the relationship, which some participants alluded to. However, this perspective changed for some participants over-time.

Femi: don't want the lady to be thinking 'oh I'm going to have to look after him all these years'…I'm pretty sure the lady might not see that as a burden cause obviously it's a relationship and two people are meant to look after each other but there probably may be that sense from the guys perspective(…)I don't like burdening anyone so keep quiet(…)if its just having a girlfriend…I think I might be like that but if its someone I know I wanna do this with for the rest of my life(…)I will try not be like that

Mike: [*SCD*] requires me to rely on other people…that's draining (…)no one really wants to look after someone fulltime(…)and not everyone's available all of the time(…)they're in the position where they're looking after someone but they haven't really done that before.

Dayo: I felt guilty they have to take this time out and spend time with me. With my ex I didn't want her to have to take time off work(…)I didn't want her to come into the hospital everyday checking up on me…so its more I'm conscious of how much goes into looking after me so when I get crisis I always feel like 'oh is this my life'…it's a bit shit(…)I think I kind of got over that and then just appreciate that whoever is meant to be for me they will take it on the chin

4. DISCUSSION

4.1. Summary of Findings

This study set out to explore the experiences of how SCD impacts on romantic relationships for men. The findings suggest that romantic relationships are impacted by SCD in numerous ways. Due to its unpredictable and debilitating nature, participants expressed that SCD prevents them from participating within societal and cultural 'norms' within romantic relationships, such as the ability to partake in 'typical' date activities. Similarly, participants found that SCD prevented them from having and adhering to 'stereotypical masculinity', for example, being a "provider", "strong", or "talking about their feelings" within romantic relationships. This contributed to a desire to hide their condition, to appear more 'normal' and to maintain social and cultural norms. The invisible nature of SCD supported participants to hide their condition, however, as a result, they felt isolated and reported struggling without social support. Correspondingly, SCD was observed to impact upon participants' emotional and mental well-being, as well as their physical well-being. Limited knowledge and awareness of SCD additionally contributed to participants preferring to hide SCD, due to societal misconceptions and stigma. These were often from the general public, HCP's, employers, and schools, but were also experienced amongst friends, family, and within romantic relationships. Despite this, participants stressed the importance of revealing and disclosing their SCD to romantic partners, due to its hereditary nature, and the possibility of future children inheriting the condition. Difficulties regarding disclosures were discussed, such as when and how to disclose and the resulting impact on partners and relationship dynamics. Significantly, participants' relationship with their SCD was observed to change over time, illustrating the changeability of their views and attitudes, and the notable impact of age.

4.2. Discussion of findings

4.2.1 'Masculinity'

An intersectional lens will be used to discuss findings as participants discussed

their experiences of being a man in society with a health condition, and the resulting pressures and expectations within romantic relationships. For example, participants voiced a desire to be “providers”, “breadwinners”, and offer “security”, however, the physically debilitating nature of SCD, left them feeling “vulnerable, inferior and weak”. To compensate, participants concealed their SCD, in order to appear more “masculine” and like a “lads lad”. Research supports this, suggesting that men with SCD are less likely to show pain catastrophising levels compared to women (Matthie et al., 2016). Participants referenced the expectations and pressures of ‘masculinity’, with one participant stating that it is “more on females to be emotional”. These generalised, gendered understandings of ‘appropriate’ male behaviour also seem to intersect with norms in African and Caribbean cultures, according to the results of the present study. Furthermore, societal, gendered discourses and notions of masculinity, have also been reported by other men with chronic conditions (Carr et al., 2017; Rowe, 2018). This demonstrates the preferred, dominant social position expected of men, as outlined by the hegemonic masculinity framework (Connell & Messerschmidt, 2005; Gannon et al., 2010; Mahalik et al., 2007).

However, participants additionally spoke about their attitudes having changed with age, with more equal non-gendered roles within romantic relationships becoming more accepted over time. Participants talked about showing weakness, speaking out about their difficulties, and allowing support from respective partners, all of which do not abide to the ‘hegemonic masculinity’ framework. Previous literature has suggested that gendered discourses are erased by society when perceiving individuals with disabilities, Hunt et al. (2021), which may have some parallels with what is perceived of individuals with chronic conditions. For example, common stereotypical perceptions of individuals with physical disabilities include that they are weak, helpless, and incompetent; thus ‘masculinity norms’ are not expected for these individuals (Crawford & Ostrove, 2003). This may have contributed in the current study, to participants’ desires to not appear weak or vulnerable, and to the adherence to gendered discourses within romantic relationships. Perhaps romantic relationships are experienced as a safe space to rebuild and confirm these preferred gendered roles; Liddiard (2014), which individuals with SCD may otherwise they feel excluded from.

4.2.2. ‘Missing Out’

Participants addressed the detrimental impact of SCD interrupting ‘normal’ developmental trajectories such as difficulties attending school, participating in activities with friends, and going on romantic dates. Consequently, participants described fewer opportunities to develop and experience romantic relationships. The unpredictable nature of SCD, and extended hospital stays were also found to impact upon participants’ feelings of isolation, due to reduced socialisation and missing out on significant life events. Not feeling able to ask for support or speak openly about SCD due to wanting to adhere to ‘hegemonic masculinity’, resulted in even greater isolation and increased psychological difficulties, illustrating a cyclical interactive effect. This has been shown within other research in SCD, with hopelessness and psychological difficulties related to pain, hospitalisation, interruption to life, and reduced socialising. (Anie, 2005; Burlew et al., 2000; Derlega et al., 2014; Matthie et al., 2015; Osunkwo et al., 2020; Thompson et al.,1992; Thomas & Taylor, 2002).

Again, masculinity notions were evident. Participants described not feeling “well enough” to “impress” their female partners, perhaps reflecting an avoidance of social situations, within which they feel unable to ‘perform’ as they would be expected. Research suggests that limited socialisation during childhood and adolescence can hinder the development of a healthy sense of self (Arnett, 2000; Erikson, 1968; Marcia, 1980). This lack of positive self-identity has additionally been linked to loneliness, seeing oneself as different, reduced illness coping, and concealment of diagnosis (Kamilowicz, 2011). In turn, increasing the chances of psychological difficulties. Correspondingly, participants described the negative impacts of SCD on how they feel about themselves and their mood; “tiring, draining, effecting my spirit”.

The desire to have a ‘normal’ life was evident throughout the data. Participants spoke optimistically about what they imagined life might be like without SCD; they hypothesised that they would have more confidence, play more sport, socialise more, travel, and have different abilities and priorities. Imagining life without SCD, may indicate that participants were experiencing SCD as a loss of a ‘normal’ life. Individuals with SCD have indeed been found to over-exert as a

result of working hard to 'appear normal', triggering physical health crises (Thomas & Taylor, 2002). Furthermore, researchers found that if this drive to live normally was not met, it resulted in depressive states, which feeling was echoed within participants' responses within the current study. Similar phenomena have been shown within research into other chronic health conditions; Bulgin et al. (2018) and Kaushansky et al. (2017), whereby individuals who felt that their condition made them deviate from 'normative' expectations, have been found to hide their illness identity to avoid rejection, pity, and being seen as weaker or different.

Feeling excluded from 'normality', may also arise as a result of living within an ableist society. In addition to physical pain, and 'hegemonic masculinity', the lack of accessibility within society for those that require adjustments, such as those with health conditions such as SCD, creates additional barriers (Jenerette et al., 2014). Within the global Covid-19 pandemic, individuals with SCD were advised to shield for a significant period of time, disrupting their opportunities for participating within 'normal' activities and for developing romantic relationships. Consequently, shielding may have contributed to participants' feelings of missing out', impacting detrimentally on mental and emotional well-being. Nevertheless, a few participants discussed living life as 'normally' as possible, regardless of needing to shield due to SCD. Whilst exploring what may have made this difference in approach possible, is beyond the scope of the current study, tentative and relational observations suggest perhaps positive impacts of psychological therapy and older age contributed. Participating within psychological therapy may have helped one participant to change his relationship with SCD (Thomas, 2000; Thomas et al., 1999). The older age of another participant may also suggest an increasingly positive outlook on life, as participants grow older (Caird et al., 2011).

4.2.3. Lack of Awareness and Knowledge

Participants discussed the lack of awareness and knowledge of SCD within society. This lack of understanding results in misconceptions and SCD-stigma, which impacts upon participants' openness about their condition and support-seeking. SCD's invisibility may contribute to the reduced awareness, knowledge, and support from others. For example, individuals with SCD have to

fight harder for their rights, due to often needing to 'prove' their condition in order to be believed (Bulgin et al., 2018; Campbell et al., 2010; Jenerette et al., 2014; Royal et al., 2011).Campbell et al. (2010) found that individuals with SCD recognised the lack of SCD knowledge within their networks. Participants within the present study similarly disclosed a lack of awareness and knowledge from HCP's, who treated participant's incorrectly, causing significant long-term consequences. Furthermore, participants were stigmatised, disregarded, and not believed by HCP's with regard to pain management. For example, participants reported being offered paracetamol when stronger medication was required. There is a wealth of literature to support these reports (Jenerette & Brewer, 2010; Lattimer et al., 2010). Indeed more recently, this has been reported in the media, whereby Evan Smith, a 21-year old young man from London with SCD, died due to being denied oxygen when he needed it. This was reported as caused by HCP's failing to recognise the significance of his symptoms, and lacking understanding of SCD, without having had any specific training on managing SCD (BBC, 2021). Limited awareness and knowledge amongst HCP's may result in individuals with SCD feeling increasingly hopeless about the ability of the general public, and indeed those in their closer systems, i.e. romantic partners, to understand their condition. This contributes to participants preferring to manage their condition outside of healthcare systems, and keep their condition hidden (Jenerette et al., 2011; Thomas & Taylor; 2002). This lack of awareness and education of SCD, and patients own mistrust in healthcare systems has been researched with similar results (Bulgin et al., 2018; Campbell et al., 2010; Jenerette et al., 2014; Martin et al., 2018; Tanabe et al., 2007; Thomas & Taylor, 2002). Having a pessimistic outlook towards healthcare systems in the presence of stigma and discrimination, as opposed to engaging fully and optimistically, has indeed been found to be protective for patient health outcomes, whereby a pessimistic outlook is seen to buffer against the reality of detrimental impacts of poor support (Stanton et al., 2010).

Similarly, schools and employers were seen by participants to lack awareness of SCD and wrongly accuse participants of being 'problem students'. Participants experienced that adjustments within employment were not always made, demonstrating an ableist society, naïve of the difficulties these individuals experience (Atkin & Ahmad, 2001). These experiences are likely to

impact upon individuals' self-perceptions, and their future life trajectory, given the relationship between misconceptions, stigma, stereotyping, and psychological well-being (Adeyemo et al., 2015; Holloway et al., 2016; Wakefield et al., 2017). Participants additionally discussed misconceptions and stigma existing within particular cultural views of SCD. One participant mentioned that his family thought he 'would faint if he was touched'. Another participant described that their family and community saw SCD, as a consequence of having bad karma from a past life. These beliefs about SCD were observed to affect participants' self-perception, particularly when it resulted in others refusing to date these individuals. Previous literature similarly discusses these misunderstandings and stigma surrounding SCD; for example, Schneider (2017), found that individuals within their communities linked SCD to witchcraft. Furthermore, Ani et al. (2012) found that individuals with SCD believed their family members felt SCD was something to be ashamed of, to keep a secret, and discriminated friendships over.

Due to these SCD-related stigma's, misconceptions, and lack of understanding, it is understandable that individuals may feel isolated, and seek solace in other individuals with SCD. In particular, other men with SCD, uniting over their shared, relatable experiences, allowing participants to feel understood. Indeed research suggests that knowing others with SCD acts as a buffer for racism, depression, and pain itself; Mougianis et al. (2020); Jones et al. (2021), and Phan (2020), found that empathy disparities for SCD specifically, are rooted in relatability of the disease.

4.2.4. Sexual and Intimacy Difficulties

Stigma and limited understanding of SCD within society may also contribute to individuals' hesitancy to start romantic relationships. For some participants, their romantic partners' limited understanding and compassion for their experiences with SCD, contributed to relationship difficulties or relationship breakdown. One participant recalled being teased due to priapism. Whilst not discussed by the participant, this experience may impact future relationships and lead to fears of embarrassment and ridicule. Indeed, literature suggests that priapism is reported as the main reason for sexual dissatisfaction within this population (Adeyoju et al., 2002). However, most participants shared that their sex life was

not affected by SCD, apart from when pain or fatigue interrupted or prevented sexual activities. When asked about intimate /sexual experiences, some participants had to be prompted to discuss priapism. Other difficulties mentioned within the literature such as sperm motility, delayed puberty, or infertility; Cobo et al. (2013); Duffy, (n.d.); Smith-Whitley (2014), were not brought up by participants. This may have been due to participants feeling uncomfortable to discuss their sexual relationships, due to its intimate and personal nature (Adediran et al., 2013; DeBaun, 2014). However, given that participants spoke about upholding notions of masculinity, and male sexual scripts seem to depend on male physicality and sexual skill, it was predicted this would be voiced more (Sakaluk et al., 2014). Alternatively, the lack of discussion around sexual difficulties, may be as participants had not experienced sexual difficulties, or been aware of the association between certain sexual and fertility difficulties and SCD.

4.2.5. Being a burden

Participants discussed thinking about the impact of SCD on their partner's, and the subsequent effects of this on themselves and their relationships. Stewart & Brindle (2021) suggest that romantic partners are most likely to co-experience the illnesses, with diagnosed individuals, which was reflected within participant responses. Some participants referred to their partners as carers, whilst one participant described the intense support their partner provided, in comparison to friends. Previous literature suggests that this level of involvement may restrict individuals from freely expressing their sexuality within a romantic-relationship, due to the overlapping roles of a romantic partner and carer (Bach & Bardach, 1978; Knight, 1983). Contrastingly, few participants, acknowledged this intense level of support from their partners as a positive. Indeed Coyne et al. (1988) suggests this level of involvement may occur as the partners own QOL may depend on how their diagnosed partner manages their condition. Other literature suggests that dependency may also infact increase levels of intimacy (Care Alliance Ireland, 2017).

It is hypothesised that these specific participants' older age may have contributed to these feelings of positivity, from higher levels of support, whereas younger individuals have been found to deem this level of support as

undermining of their masculinity and autonomy (Gerschick et al., 1995). Expectantly, this was observed within the responses of some participants; they discussed “not wanting to be pitied” and feeling like “a burden” as reasons for hiding their SCD from partners. These attitudes may have arisen as a result of wanting to adhere to ‘masculinity norms’, for example, participants described feeling “embarrassed” at having to be physically reliant on their partner; appearing “weak”. This has been highlighted of men in other literature exploring the experiences of men with SCD and cancer (Derlega et al., 2018; Duffy, (n.d.); Rowe, 2018) This may be consistent with the Social Exchange Theory; Thibault & Kelley (1959), which focuses on the importance of maximising rewards in a romantic relationship and minimising costs, in order to feel relationship satisfaction. In line with the Equity Theory; Walster et al. (1973), the partner receiving the greater reward to loss ratio, may experience guilt or shame. Thus individuals with SCD may feel that they are receiving greater reward from their romantic relationship, compared to their partners, and feel they are unable to provide this support back, due to their health condition, leaving them feeling ‘a burden’.

Participants also reported romantic partners leaving relationships due to difficulties witnessing SCD crises. This was in spite of partners originally stating that they could tolerate seeing the potential effects of SCD. The difference between visually witnessing the impact of the condition and hearing about its effects, may have contributed to partners feelings of helplessness and frustration, resulting in distancing within the romantic relationship. This effect has previously been reported within SCD, cancer, and cystic fibrosis (Broekema & Weber, 2017; Rowe, 2018; Thomas & Taylor, 2002). Other reasons for relationship breakdown included partners leaving due to feeling unable to look after their partners with SCD, and being dissatisfied with reduced ‘typical’ relationship activities such as partaking in sexual and intimate activities. These reasons for leaving are expected to effect individuals’ self-perception about their own abilities, and perhaps exacerbate the ‘burden’ narrative. Concerns about being a ‘burden’ may additionally lead to the reluctance to appear physically and emotionally vulnerable and a reduction in the amount of support sought from partners. This corresponds with research, which demonstrates that negative self-perception significantly mediates the relationship between

isolating themselves and coping alone, and intimacy, communication, and trust (Thomas & Taylor, 2002). However, in contrast to this 'burden' narrative, all intimate and romantic relationships can be seen as interdependent, regardless of whether or not a chronic condition is present. For instance, at some point in a romantic relationship, it may involve providing care for one another; if the partner acquires emotional support, or acquires a health concern themselves, or when growing older together and having to rely on one another (Care Alliance Ireland, 2017).

4.2.6. Disclosing to partners and reproductive attitudes

Despite the difficulties mentioned above, causing participants to want to hide their condition, participants additionally stressed the importance of disclosing their SCD status to romantic partners, as also previously reported within the literature (Duffy, n.d.; Heller et al., 2016; Rowe 2018). This was especially salient as romantic relationships developed and became more serious, due to the heritability of SCD and the possible consequences for future children. Difficulties deciding when and how to disclose their condition was discussed, with participants displaying a desire to control and mange this process carefully. These difficulties and tensions have been discussed within previous research (Derlega et al., 2018; Gallo et al., 2010; Smith & Aguirre, 2012). Participants exhibited a preference to disclose early on within relationships, to avoid the risk of relationship-breakdown occurring at a later stage, leading to disappointment and heartbreak. A few participants expressed their frustration at not being able to be romantically involved with friends with SCD. This restriction around partner choice is reflected within previous literature (Duffy, n.d.; Gallo et al., 2010; Phan, 2020; Rance & Skirton, 2019).

Participants voiced the unhelpfulness of a lot of partners often not knowing themselves whether they had SCT. In response, participants stressed the importance of their partners being tested early on within the relationship. In addition, participants discussed ideas for increasing awareness of SCT within the wider population, for example through increased information provided within schools, and compulsory blood tests. Significantly, research has found that individuals with SCT lack awareness of reproductive implications; Treadwell et al. (2006); Williams-Smith (2015), and often exhibit denial regarding their

carrying of the SCT (Smith & Aguirre, 2012). This may result in individuals with SCD feeling an increased sense of responsibility for raising awareness of SCT and for taking precautions within their own relationships, as observed within the data, through asking partners to get tested early on.

With increased age, participants observed that their attitudes towards disclosure changed and they became more open about SCD. This may be connected to changes in maturity, changes in the individuals' relationship with their SCD, and/or increased desires to raise awareness of SCD. Being in more long-term and serious romantic relationships may also have contributed to the changes in attitudes over time, due to the significant decision-making that needs to take place, for example when thinking about having children. Reasons participants gave for disclosure included, not wanting to deceive their partner, not wanting to have their partner find out about SCD in a 'shocking way', and wanting more support with SCD. This may perhaps imply that disclosure may correspond with symptom severity, such that individuals are more likely to disclose SCD, if they have a higher chance of frequent, significant crises, which require additional support. Indeed Derlega et al. (2018) found disclosing SCD resulted in catharsis and emotional relief for individuals with SCD. This was reflected within the present study, with one participant sharing that "a load shared is better".

Most participants held firm beliefs about not wanting their child to inherit SCD, due to experiencing the detrimental effects of SCD first-hand. Therefore, they felt strongly that they should not reproduce with another individual with SCD or SCT. Previous literature has documented similar beliefs amongst this cohort, with individuals not wanting their children to experience the pain, stigma, and psychological difficulties they themselves faced (Ross, 2015). However, two participants illustrated a preference to not restrict their partner choice, and chose their romantic partners regardless of SCD-status, citing that the right partner was more important to them, than ensuring future children would not have SCD. One participant had children with SCD and explained that due to his experience of the condition, he had everything in place to support his child. This is a similar attitude to those found within Rance & Skirton (2019), Smith & Aguirre (2012), and Severijns et al. (2021), whereby pregnancy decision-

making depended on participants' own experiences of SCD, and their beliefs about their ability to manage their child's SCD.

Despite their mention within various pre-existing literature, genetic counselling, reproductive options, and pre-genetic screening, were only discussed by one participant within the study. This may be due to the biological sex of participants meaning that they would not carry or birth their children, therefore not thinking as much about this. Literature support this hypothesis, finding that females often have a larger and more final say in reproductive decisions (Severijns et al., 2021). Additionally, the limited discussion about reproductive processes may also be due to a lack of knowledge about different reproductive options within the SCD community (Gallo et al., 2010; Phan, 2020; Severijns et al., 2021; Williams-Smith, 2015).

4.2.7. Maturing, Adapting, and Acceptance

An overarching theme identified within participants' responses, was the changeability within participants' views and attitudes over time. Becoming more open about SCD, and adhering less to 'masculine norms' appeared to support the individuals with their emotional and mental health difficulties. Research has suggested that with age, comes increased understanding, greater confidence, and higher levels of self-acceptance regarding SCD, as well as higher use of self-care resources (Caird et al., 2011; Jenerette & Lauderdale, 2008; Jenerette et al., 2011). Participants discussed working towards accepting their condition, which in turn supported them to change their relationship with SCD; positively impacting on how SCD was managed. Acceptance was developed through learning more about SCD, giving SCD meaning, and finding justification for their suffering, all of which is supported by previous literature (Asnani et al., 2017; Caird et al., 2011). Participants mentioned moving towards being appreciative of their condition, for instance, SCD making them more "humble", "optimistic", "determined", and "grateful for being alive". Some participants discussed eventually seeing SCD as a "blessing" and "superpower". This appreciation has been reported in previous literature (Coleman et al., 2016; Cousins et al., 2017; Dyson et al., 2010; Thomas & Taylor, 2002). Caird et al. (2011) additionally discusses the positive impact i.e. on identity and active coping, of external acceptance, gained through being open about their condition. This was

illustrated in the current study through participants stating that they wanted to disclose to help others, through advocacy and raising awareness of SCD. Participants reported reduced distress and increased hopefulness as a result of internal and external acceptance, as found within previous literature (Kaushansky et al., 2017).

4.2.8. Racial Disparities

A notable absence within the data was the mention of race. Despite literature suggesting that racism and racial disparities are a common experience for individuals with SCD; Atkin & Ahmad (2001), Foster & Ellis (2018), Haywood et al. (2013), Labore et al. (2017), and Phan (2020), only one participant mentioned race, stating that the reason for limited knowledge and awareness of SCD, was due to its predominant prevalence within Black African/Caribbean communities, which other literature has also cited (Anionwu & Atkin, 2001; Phan, 2020). Whilst it is possible that racism may not have been central to the experiences of the other participants interviewed, there are multiple reasons why race may not have been discussed. Participants were not directly asked about their views on racial discrimination and therefore may have not known if it was relevant to mention within interviews. Additionally, as I, the interviewer, am from a different racial and ethnic background, participants may have felt that there would be a lack of understanding if they were to disclose racially discriminatory experiences. The stigmatisation of SCD as a “black disease”; Bediako & Moffitt (2011); Gallo et al. (2010); Smith & Aguirre (2012), may also have led to participants wanting to distance themselves from this narrative. For instance, knowing other people from different racial backgrounds that have experienced the same SCD-related treatment, may have led participants to connect their experiences to health-related discrimination, as opposed to racial discrimination. Notably, the layered nature of stigma they face can lead to difficulties describing the influence of stigma and discrimination on this population. Indeed, many studies conflate racism and stigma, Bulgin et al. (2018), and racial and health-related discrimination, given that these can occur individually, as well as being intertwined (Kripalani et al., 2010).

4.3. Implications and Recommendations

Implications and recommendations for research, policy, and clinical practice will be discussed. The current findings are also relevant for individuals with SCD, as well as their family members, friends, and romantic partners.

4.3.1. Implications for Practice

4.3.1.1. Therapeutic Intervention:

The current analysis found that participants valued the consideration of their whole context when working with HCP's in the healthcare system. They discussed other ways SCD impacts them in addition to its physical symptoms, showing the need for holistic approaches to assessment. Adegbola et al. (2012), supports HCP's taking a more holistic approach, by considering psychosocial factors. More thorough, holistic working, would allow for more appropriate onward referrals to different disciplines, for example, to psychology. Participants mentioned finding psychological therapy beneficial in helping them to manage SCD-related difficulties, such as the impact of SCD on their identity, relationships, and QOL, which previous literature supports (Foster & Ellis, 2018; Matthie et al., 2019; Thomas, 2000). Given that acceptance of SCD, and nurturing of resilience, were both found to be helpful for participants, perhaps utilising acceptance, hopeful, and strengths-based therapeutic models within psychological therapy, may be beneficial. Approaches such as Narrative Therapy; White & Epston (1990), and Acceptance and Commitment Therapy; Hayes et al. (1999), may support individuals to distance themselves from the condition, re-connect with their strengths and values, and empower individuals to adapt to their chronic illness (Caird et al., 2011; Cousins, 2017). The timing of psychological support may also be an important factor to consider. As mentioned, the development of ones sense of self and identity tends to occur around 'teenagers' years, thus perhaps psychological therapy around this time, and/or just before this age, may support individuals with SCD to develop a healthier sense of self, especially considering how entrenched masculinity discourses can become for young men.

Participants also emphasised the importance of attending therapy with their romantic partners to facilitate open communication and conversations. This finding is in line with previous research describing the dyadic effect of chronic

health conditions (Berg & Upchurch, 2007). Couple's therapy may support partners to help individuals with SCD to manage the condition, through positively reinforcing the individuals' efforts to cope, which has been found to be beneficial within a chronic pain population (Keefe et al, 1996). Therapeutic support for couples may also be beneficial to support with reproductive decision-making (Severijns et al., 2021). The wider social network and context around the individual, beyond romantic partners, should also be considered within psychosocial interventions, perhaps using Brofenbrenner's (1979) 'Ecological Model' as a framework. Systemic approaches are more commonly used within children and young adult services, however the adoption of systemic and family-based approaches within adult services for individuals with SCD, have been found to be beneficial too (Schwartz et al., 2007).

Given the impact of 'masculinity norms' of not "opening up about emotions", therapists should find ways to encourage men to feel comfortable to uptake and participate within psychological therapy. For instance, adapting the therapeutic approach to incorporate metaphors and less direct talking about individuals' personal experiences, may potentially increase the acceptability of therapeutic support. Connecting individuals with peer support groups, or perhaps a buddy/mentor system, and networks involving other men with SCD may also be beneficial as suggested by participants. These collective and community approaches; Holland (1991), may be beneficial in creating familiar and community spaces to discuss relatable and shared challenges and the stigma experienced. This will support to value all layered aspects of an individual, such as all their intersecting identities (Burnham, 2008), impacted by SCD. Furthermore, community approaches position the individuals with SCD as experts in their own care, enabling collaboration and peer-support amongst other individuals with SCD. Collaboration between SCD charities, and NHS services may enable a provision of organisational structure to support this, although, it would be important to ensure that men with SCD took the lead themselves in determining what support is helpful, and ensuring their ideas are followed through (Afuape & Hughes, 2016).

4.3.1.2. HCP Awareness:

Participants expressed the importance of psychological therapists and HCP's requiring education on SCD and the condition's implications in order for support to be beneficial. Cultural humility and cultural curiosity; Mosher et al. (2017), may support HCP's to better their understanding on how SCD is understood within the culture and communities that service users live in. This is deemed valuable in improving healthcare outcomes for individuals with SCD (Isaac et al., 2020). Furthermore, culturally-sensitive communication and bias-training for HCP's has been shown to reduce the negative effects of racial discordance; Phan (2020), and therefore could perhaps be integrated when working with this population. Indeed, increasing ethnic and racial diversity amongst HCP's, has too been found of significant importance, when assessing and treating individuals with SCD (Isaac et al., 2020).

It is also important that HCP's listen closely to patient wishes regarding medical interventions, respecting the expertise that individuals with SCD have about their condition and their bodies. Phan (2020) suggests that SCD is highly variable in its presentation and its response to treatment, with many symptoms difficult to tangibly and objectively measure. Therefore, as the participants within the present study explained, it requires a personalised approach whereby HCP's gain insight from the patient to inform care. Participants implied that prejudice and stigma can interfere with the HCPs' willingness to listen. Assumptions or misjudgments about patients' needs may prevent patients' experiences and wishes being heard; consequently, these need to become more conscious, and actively addressed by healthcare services.

4.3.1.3. Talking about sexual difficulties within the healthcare system:

HCP need to be aware of the specific challenges within romantic relationships that individuals with SCD may face. In order to best support individuals with SCD, HCPs need to be willing and able to sensitively discuss sexual difficulties, reproductive concerns and decision-making, and communication within romantic relationships. HCP's should consider beginning such conversations at the point of transition to adulthood, at which time sexual activity is an important consideration for young people, and closely related to QOL (Browne & Russell, 2005; Tepper, 2000).

Research suggests that HCP's often experience discomfort when discussing sex, due to embarrassment, uncertainty regarding what to say and do, and limited time within appointments (Blackburn et al., 2015; Guest, 2000; Weerakoon, 2001; McLaughlin & Cregan, 2005; Shuttleworth, 2010). Perhaps specific training may support HCP's to feel more confident facilitating these conversations; in turn, it is hoped that individuals with SCD will feel empowered in regards to their sexual self-esteem and well-being, and ability to communicate their sexual needs, especially as this is important for their mental and physical well-being (Lee & Fenge, 2016). Psychological therapists may be best placed to facilitate and normalise these conversations, given the privilege they hold in discussing other sensitive, intimate and emotional topics with individuals. The increased occurrence of conversations with HCPs may act to reduce embarrassment, shame, and the extent to which individuals with SCD feel they need to hide sexual difficulties or concerns. Indeed, research has shown that patients appreciate and express relief when conversations about sex and fertility are started by HCP's (Aizenberg et al., 2002; Duffy, n.d.; Walters and Williamson, 1998).

Access to knowledge and support regarding fertility issues, priapism, and the impact of SCD on romantic and sexual relationships, is required early on within young men's lives. Research has shown that only 7% of patients who had not experienced priapism were aware that priapism was a SCD-related complication (Kheirandish et al., 2011). Greater collaboration between haematologists and urologists may support in increasing awareness of and support for individuals experiencing priapism (Adeyoju et al., 2002). Health education awareness campaigns may additionally help to increase awareness and increase health-seeking behaviours amongst men with SCD-related priapism (Idris et al., 2020). Wider awareness of reproductive options is also required to reassure individuals with SCD, for instance genetic counseling and understanding genetic risk factors. In an increasingly multi-ethnic world, individuals with SCD are likely to present to HCPs outside of specialist services, and therefore knowledge and the provision of support is required from general practitioners and within primary care settings too.

4.3.2. Wider implications

More awareness and knowledge on SCD and its impacts is additionally needed within the general population, including within education and employment. Increased awareness is expected to reduce the negative effects of stigma, ignorance, and mis-information experienced by individuals with SCD. Research found that showing educational videos and interventions of the patient experience of individuals with SCD, to HCP, decreased negative attitudes and increased positive attitudes towards individuals with SCD, highlighting the contribution of misconceptions to the stigma surrounding SCD (Haywood et al., 2011; Haywood et al., 2015). Increasing education about SCD for example within schools, may therefore help to reduce misconceptions and misinformation about SCD. This is especially important given that in comparison to other chronic conditions, SCD is rarely, if at all, discussed within schools (Phan, 2020). Training and education in these environments may also help to increase the quality of relationships for individuals with SCD, by making it safer for individuals to speak about their condition and receive support from those around them, without fear of discrimination and stigmatising attitudes. Furthermore, increased awareness may help to improve testing for the condition and increase the number of people who are aware of whether they have SCT.

Increased awareness and knowledge of SCD is also needed within the community, especially amongst individuals' friends and families. This would hope to shift untrue and unhelpful narratives, allowing for more factual and better understood SCD-narratives. Psychologists can support with this, through collaborating with individuals with SCD to explore the best approach. For example, what information individuals with SCD would like shared, how they would like to share this, and with whom. For instance, working with local community centres and places of worship may be explored as spaces to share knowledge and awareness. Creating safe spaces where individuals feel able to openly disucss, with the hope that SCD false narratives and myths can be questioned and addressed. Hosting talks, creating and distributing accessible informative leaflets, creating podcasts, and collaborating with well-known influencers with an interest in SCD, may also be impactful. Some of these

initiatives may already be occurring across communities; however further government funding will help support extend the reach.

At present, funding, resources, and research is limited; Bahr & Song (2019), exhibiting health inequity (Howard et al., 2009). A commitment to distributing equitable resources across primary care, community, and inpatient settings is required, to address and eliminate the health disparities for this cohort (Valrie et al., 2020). It is hoped that increased awareness and understanding may subsequently improve the funding and resource available to support individuals with SCD. National level campaigns are needed for this. Given that race and culture are intertwined with economic resource, addressing racial discrimination at a systems level is additionally required in order to improve health outcomes for individuals with SCD. Cultural awareness and diversity training may support with raising awareness of, and ultimately reducing, racial and ethnic disparities within healthcare settings (Trent et al., 2019).

In line with the social model of disability, it is important to acknowledge that aside from their physical impairment, individuals with SCD often can feel oppressed due to social norms, such as gender stereotypes, but also the lack of adaptations made for them within society. As SCD is invisible, and individuals are often not believed about their condition, particularly when unable to act in performative ways expected by society as ‘acceptable’ for a man, this can leave individuals feeling ‘othered’. This can result in the internalisation of difficulties, whilst also placing blame and responsibility to manage SCD within individuals. Rather, it is important that responsibility is positioned within wider political and economic structures, which contribute to the emotional and personal consequences of having a chronic health condition (Lidiard, 2014). Collective narrative practices; Denborough (2008) and community psychology may be beneficial in generating novel alternative stories about living with SCD, challenging dominant discourses about ‘masculinity’ and ‘illness’. The emergence of alternative societal narratives may contribute to a shift in culture of how SCD is spoken about, interacted with, and managed.

4.4. Future Research

Future research should explore the perspectives of both the individual with SCD and their partners. Joint interviews could be used to gain a 'couple's perspective' on the impact of SCD on romantic relationships, providing an insight into how stories are shaped differently when in conversations with one another. This may further contribute to the development of support for individuals with SCD, given that speaking with one individual within a relationship dyad does not provide a complete description of the challenges that may be present (Jordan et al., 2021). This research may also draw more explicitly on the Social Exchange Theory; Thibault & Kelley (1959), exploring reward and cost ratios within the romantic relationship. Future research should also explore the experiences of individuals with SCT. Results showed that reproductive decisions were of major importance in romantic relationships; therefore, recruiting individuals with SCT would enable more widespread exploration of reproductive decisions within this population.

All participants in the current study were heterosexual and discussed monogamous relationships. The issues identified within these types of relationships, such as reproductive issues and adhering to 'masculinity norms', may present differently within other types of romantic relationships. Therefore, future research looking at LGBTQ+, and/or polyamorous relationships, may further provide further insights into the challenges experienced within romantic relationships for individuals with SCD. The present research also exclusively explored the experiences of men. Whilst there is more research generally on the experiences of women with SCD, there is no study to date exploring how SCD affects romantic relationships for women, or non-binary individuals. It would be of interest to compare these future findings with the current study.

One of the central themes which emerged within the current study was stigma. The layered nature of stigma can often make it difficult to differentiate between health-stigma, racial stigma, perceived and enacted stigma, and internalised stigma. Further research is needed to unpick and pinpoint the influence of different types of stigmas on the lives of individuals with SCD. Whilst most research focuses on stigma experienced within the healthcare system, the stigma experienced within individuals' close networks, from family, and friends, warrants further attention within research (Bulgin et al., 2018). Additionally,

research should be conducted to focus on normative views people hold, for instance, attitudes towards being in a relationship with someone with SCD, including views on sex, intimacy, and partner roles.

Lastly, the relationship experience and relationship status of participants within the present study was varied, making it difficult to determine what impact prior relationship experiences and current relationship status had on results. Therefore, future research should explore the impact of current relationship status, previous relationship experience, and the length of participants' current relationship, on their views of how SCD affects romantic relationships. Furthermore, as the present participants differed in age, it would be interesting to explore further how SCD impacts romantic relationships within elder generations, but also amongst younger teenagers, who may be thinking about romantic relationships and starting to date. The impact of individuals' health status on their perceptions and experiences is also important to consider within future research, given that this is not static and may change over the life trajectory. Although participants within the current study voiced differences in their views over time, it is important to explore the perspectives of younger individuals who may be experiencing increased challenges within their relationships at the time of the interview. Using prospective studies, in comparison to one-off interviews, would enable the exploration of individuals' experiences over time without retrospective biases potentially impacting upon findings.

4.5. Critical Review

This research will be evaluated using Yardley's (2008) procedures to demonstrate the quality of the research processes applied.

4.5.1. Sensitivity to Context

4.5.1.1. Immediate Context:

Romantic relationships can be an intimate and sensitive topic to talk about, especially when discussing them in the context of a chronic health condition,

such as SCD, due to the additional stigma faced. This may have impacted how openly participants felt they could speak about their experiences.

My contrasting identity as a female, from a different racial and ethnic background, and as someone without SCD, may also have influenced participant responses. My identity as a female may have also influenced how I approached the interview process; for example, the way I asked questions about intimate topics may have been affected by the fact I was interviewing individuals of the opposite sex. This will be discussed more in the reflexivity section of this chapter.

4.5.1.2. Wider Context:

The interviews took place within two significant global contexts. They occurred during the Covid-19 pandemic, and amongst the Black Lives Matter (BLM) movement, which was triggered by the murder of George Floyd in May 2020.

Due to being classified as a 'vulnerable' population, individuals with SCD were advised to shield during the pandemic. This may have put constraints on participants and impacted their responses within the interview. Individuals may have expressed their opinions on their healthcare from the position of 'isolating', and not having had any recent contact with HCP's. Similarly, participants may have felt increasingly oppressed by ableism, due to having to shield without additional support and adjustments being put in place.

All participants included within the study were Black African or Carribean men. The interviews were held during the aftermath of George Floyd's death, whilst BLM protests were occurring across the globe, and increased conversations about racial discrimination were occurring across different contexts. This may have influenced the extent to which participants spoke, or did not speak about race, perhaps due to the increased sensitivity surrounding conversations about racial discrimination at this time.

Although participants did not explicitly name these events as impacting their responses, it may have influenced responses in a more implicit way, such as what with was not spoken about.

4.5.2. Commitment to Rigour

I completed the data analysis and transcription process independently, repeating the transcription process for a second time, to ensure data familiarity and to support the development of codes. Codes were refined throughout the analytic process (Appendix 11a-11c), through repeated reading of the transcripts, until themes were identified. The identified themes were also revisited and refined throughout analysis (Appendix 11f-11h). To minimise bias within interpretations, the developing codes and themes remained closely linked to the data itself, through quotes, before also being linked to previous literature where possible. This process was supported by my research supervisor, through reviewing codes and themes identified, and through providing alternative perspectives on emerging themes. Supervision additionally helped to ensure that Braun and Clarke's (2006) TA procedure was adhered to.

4.5.3. Transparency and Coherence

Transparency within the research process was achieved through documenting why and how each research decision was made in the respective chapters, and by completing reflective accounts of the research process. The rationale for carrying out the study within this population, and for the chosen epistemological position, are also detailed within the respective sections of the thesis. A clear account of the data analytic process can be seen within the methods chapter and appendices.

Coherence is provided through a critical realist approach, which matches the epistemological position of the research. This approach allowed for the impact of SCD on participants' romantic relationships to be considered, in light of their own positions, values and experiences. These results were subsequently linked to existing literature. A coherent constructed story of the research is provided within the present discussion chapter.

4.5.4. Impact and Importance

This study is of timely importance given the lack of literature on the psychosocial impacts of SCD on men; more specifically, no existing literature has explored experiences of romantic relationships for men with SCD.

Considering that individuals with SCD are living longer, and are consequently experiencing more romantic relationships, the current scarcity of literature and knowledge within the UK in this area is unacceptable. In general, men are less likely to talk about challenges within romantic relationships, likely due to masculinity norms and SCD-related stigma; therefore, it is paramount that their voices and experiences are heard. Given the limited research within this area, the contributions of the present study are significant, in reducing the stigma and misconceptions surrounding SCD, and shedding light on the experiences of men with SCD.

It is important to acknowledge that the findings of the present research are specific to the individuals that took part, each located within a specific time and cultural context. Despite this, the findings are still of importance to other men with SCD, their romantic partners, and the wider network of people that support them. Using research to provide a platform from which men can share their experiences it vital. This was observed within the present study, with participants reporting that the interview experience provided a chance to consolidate and reflect on their experiences, and in particular, to think about the personal impacts of gender, and cultural and societal norms. This highlights that more safe spaces are needed for men with SCD to discuss their experiences. The importance of the present research was further highlighted through the participants showing interest in reading the completed report. Indeed, the distribution of the present research findings may encourage other men with SCD to talk openly about their experiences.

4.5.5. Other methodological consideration

All participants lived in large cities within the UK, and may therefore have different experiences in comparison to those living in more smaller, more rural towns, whereby there may be even less ethnic diversity, and knowledge and awareness around SCD. Furthermore, the use of a non-random sample, recruited through social media, may have increased the potential likeness of participants. Participants also did not vary significantly with regard to ethnicity and race, or sexual orientation, limiting the generalisability of findings to all men with SCD.

As described within chapter 2.4.3, there were various challenges around recruitment. Of particular, the sample size for the research was small, which questions generalisability of results. Therefore, the participants' age-range was increased in order to gain a larger sample size. However, it can be argued that increasing the age range resulted in a lack of homogeneity within the sample. As themes were generated from grouped participant data, differences in age and life stages of individual participants may not have been captured, impacting results. For example, older participants may have different views and expectations of relationships to younger participants. Grouping themes may not have captured these differences. Increasing the sample size, and tightening the age range, may have strengthened themes, and allowed for different themes to emerge.

Individual interviews were used due to the sensitive and intimate nature of the topic of interest, however, a focus group of men with SCD may have resulted in the generation of different or additional themes, produced through sharing ideas and experiences with each other. A critical realist epistemology was utilised to enable consideration of the impacts of social constructs impacting on participants' responses, as well as their lived reality. However, if a social constructionist epistemology was employed, this may have allowed for more exploration regarding how language shaped the experiences spoken about, and on how participants constructed their position in relation to wider societal discourses.

Lastly, although a SIG was consulted, and their input taken into consideration throughout the research process, this group was compromised only of HCPs. Input from individuals with SCD themselves, would have increased the potential relevance of research, however due to recruitment difficulties, this was not possible. Future research should seek to gain input from individuals with SCD themselves, at each stage of the research process, to support with shaping and designing future research into SCD.

4.6. Reflexive Review

On reflection, I was unprepared for how reluctant men might be to talk about sexual functioning and romantic relationships, and this is perhaps why priapism was not spoken about as much as I thought it would within the interviews. My own inexperience of asking and talking about sex, and my desire to reduce embarrassment or awkwardness for the participants, may have also contributed to participants' limited discussion about sexual difficulties. Holloway & Jefferson (2000), suggest that interviewing requires therapeutic skill to consider participant needs whilst conducting research. On reflection, there were times where I could have used more therapeutic skill to confront my own discomfort and asked participants for further elaboration around sensitive topics, to produce richer discussions, about sex for instance, or views on females from a male perspective. At other times, positioning myself within the researcher role was difficult, due to the familiarity of, and temptation to adopt a more therapeutic stance when discussing more difficult and emotive topics. For instance, resisting to use therapeutic skill of interpretation and reflection, to ensure participants were not influenced by my responses. Instead, throughout the interviews, I encouraged participants to be open about their experiences by being non-judgemental and authentic in my approach, holding a genuine curiosity about participants' experiences.

Whilst analysing and discussing the data, I felt hesitant to make particular interpretations about things participants had said, due to a fear about what participants may think of my analysis. I worried about participants taking offense or viewing my interpretations through an accusatory or persecutory lens, especially given my position as a woman without SCD. To minimise the impact of this on analysis, I was careful of the language I used, expressed interpretations tentatively, and minimised bias and assumptions within my interpretations through staying close to participant data. My previous work within a SCD service may also have impacted upon my assumptions about participants' experiences and subsequently my analysis, from what I observed when working with men with SCD. Additionally, coming from an ethnic culture which has similar views towards gendered identities, and being from an ethnic 'minority' background with personal experiences of stigma, may have made me more attuned to certain experiences voiced by participants. To prevent over-focusing on these experiences, I ensured I returned to the initial codes and raw

data extracts often, to ensure I was giving all data similar levels of attention. This helped to ensure that I was not over-interpreting what participants said to fit my own personal experiences and cultural ideas about what is important. In addition, I worked hard to consider subjugated and implicit narratives within the data, as a way to reduce the impact of my own subjective position, biases and assumptions. Using a reflective diary (Appendix 12) throughout the analytic process supported me to name and identify my own biases, assumptions and emotional responses to the data.

4.7. Conclusion and final reflections

The present research aimed to explore how SCD impacts on men's romantic relationships. The findings showed that men with SCD can experience significant pressure in relation to upholding societal and gender 'norms' within romantic relationships, whilst having a physical health condition. Partnered with the lack of awareness and understanding around SCD, individuals had experienced notable stigma regarding their identity as a man with SCD. This had led to individuals choosing to hide their SCD and mask the physical and psychological effects of the condition. Fears of their experiences not being believed had further increased desires for their SCD-status to remain hidden. Detrimental consequences of hiding SCD were observed, such as reduced socialisation and increased mental and emotional difficulties. Indeed, this desire to adhere to gendered discourses and notions of masculinity, in addition to 'normative' expectations, are seen in literature of men with health conditions outside of SCD, and found to result in men wanting to hide their illness. This suggests that some of the issues emerged from the data may not be purely disease-specific, and rather something that affects many men with chronic health conditions. Despite this, for SCD specifically, the present research found that being open about and disclosing their condition to long-term romantic partners was especially important, particularly due to the heritability of SCD. Disclosing SCD resulted in other benefits too, but also challenges for individuals, their romantic partners, and their relationships. Notably, participants demonstrated significant resilience and described moving towards acceptance and an appreciation of their condition over time. Increased awareness, education and understanding about SCD is required to support and normalise

open discussions about its physical and psycho-social impacts. Collaboration and co-production with individuals with SCD, whilst being mindful of inequalities and power imbalances, is required, in order to shape and provide meaningful and holistic care to this population.

In conclusion, I hope that the dissemination of this research will positively impact men with SCD and their partners and supporters, through an increased understanding of some of the unique challenges faced by men with SCD. I hope that this research can also be seen as a demonstration of my own personal support for individuals with SCD, who manage SCD-related challenges and stigma, racism, and inequality, yet show incredible resilience throughout these experiences. Although challenges may occur within romantic relationships for individuals with SCD, it is evident that there is possibility for increased psychological health and greater fulfilment within relationships, particularly in the context of increased research and a changing, more inclusive society.

5. REFERENCES

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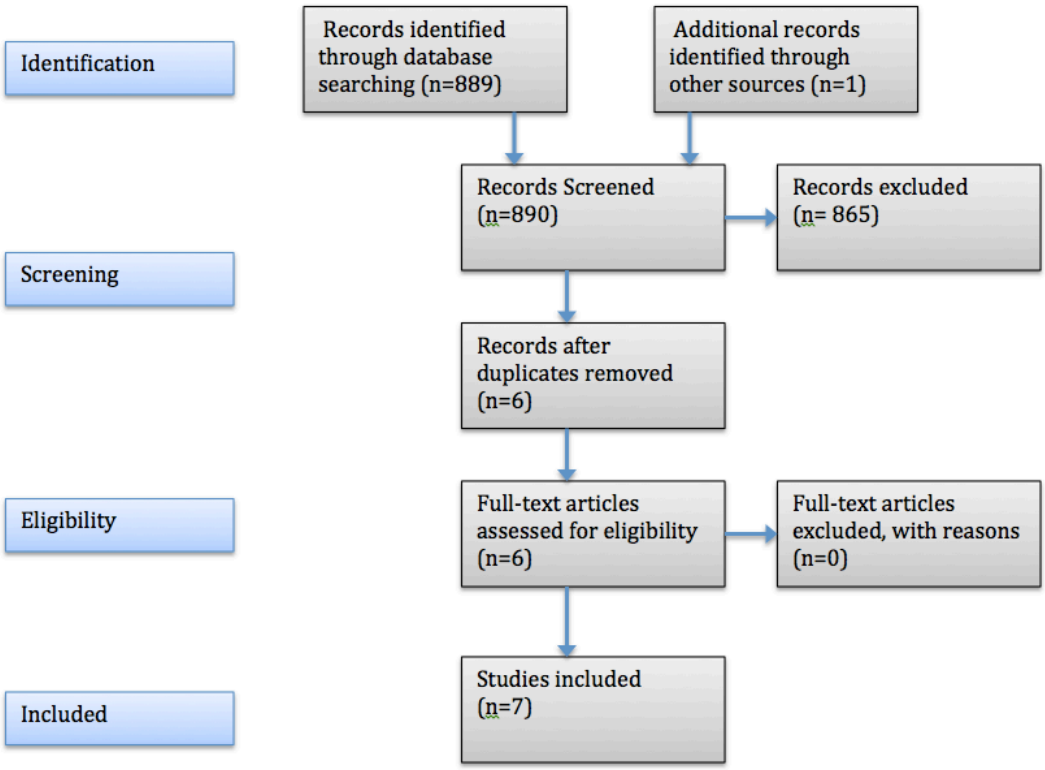
6. APPENDICES

6.1. Appendix 1 - Search Terms

("Sickle Cell Disease" OR “Sickle Cell Anaemia”)
AND
(couple* OR "romantic relationship*" OR partner* OR "intimate relationship*"
OR dating OR “sexual relationship” OR marrying OR marriage)

6.2. Appendix 2 – Prisma Flow Diagram



6.3. Appendix 3 - Summary overview of the papers included in the scoping review

Author and publication year	Country of Study	Sample and Size	Aim/Focus of Study	Methodological Design
Cobo et al., 2012	Brazil	(*n=20*) Age: 19-47 Females and Males (majority females)	To characterize the development of sexuality in adults with SCD through investigating patient's perception of their sex life, and information they had and need on this subject.	Semi-structured interview – Qualitative analysis using content analysis
Duffy, n.d.	UK	(*n=5*) Average age: 27 Men	To explore the sexual experiences of men with SCD	Semi-structured interview - Qualitative analysis
Gallo et al., 2010	Illinois, USA	(*n=10* with SCT) (*n=5* with SCD) Age: 36-63 Average Age: 47 Females and Males (majority females)	To examine the beliefs, attitudes, and personal feelings of people with SCD or SCT related to making informed reproductive health decisions.	Questionnaire items and 3 focus groups Qualitative analysis using Thematic Analaysis
Smith & Aguirre, 2012	London England, Pennsylvania USA	(*n=79*) Age: 16-63 Females and Males	Review to examine the reproductive attitudes and behaviours in people with SCD or SCT to create effective genetic counselling programs to inform reproductive decision making	Qualitative interpretive meta-synthesis (interviews and focus groups)
Rance & Skirton, 2018	Brazil, Cameroon, Jamaica, USA	Females and Males	Review to ascertain the factors that may influence women with their reproductive decisions.	Qualitative and quantitative studies - narrative approach to identify themes
Ross, 2015	USA	(*n=28*) Age: 18-52 Females	To gain knowledge about women's reproductive decision-making through exploring their motivations for asking their partners to undergo prospective genetic testing.	Interviews-Qualitatively analysed using descriptive phenomenology approach
Derlega et al., 2014	Virginia, USA	(*n=73*) Females and Males (majority females)	To examine to whom and how fully SCD patients talk to others about SCD pain, how helpful it is to talk with others about these pain episodes, and the association between talking to others about SCD pain episodes and patients' psychological adjustment and coping strategies in managing the disease	Cross-sectional study – self-report rating scales – quantitative analysis

6.4. Appendix 4 – Ethical Approval Letter

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Andrea Giraldez-Hayes

SUPERVISOR: **Kenneth Gannon**

STUDENT: Shrina Patel

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Sickle Cell Disease in young men, and its impact on relationships

DECISION OPTIONS:

1. **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/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** 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.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved, but minor amendments are required before the research commences

Minor amendments required *(for reviewer)*:

3.6. How will you protect the data when using the audio-recording device to record telephone interviews? You mention a computer, but it is now clear the connection between the phone, the recording device and the computer and data should be protected in all steps. Besides, you mention that a transcription device will be used. Which device will be used? How is the data protected in this case?

Data will be recorded and transcribed using Microsoft Teams (eg via audio call). An encrypted audio-recording device (Dictaphone) will be used as a back-up plan to record the data in case there is an error in the Microsoft Teams recording. If the data records on Microsoft Teams with no errors, the Dictaphone recording will be deleted immediately. As a last resort, if Microsoft Teams cannot be used, the interview will take place over the telephone, and this will be recorded using an encrypted audio-recording device (Dictaphone). The data from the Dictaphone will be transferred to the computer onto a password-protected file on the same day the interview takes place and deleted from the Dictaphone straight after the transfer. Microsoft Teams is managed by UEL and has been advised by UEL to use as a secure software for research interviews, and therefore Microsoft Teams will be used to transcribe the interviews, therefore the data will be protected.

4.4. It seems like you mention something different here. You say that interview data will be audio-recorded on a Dictaphone. Could you please clarify and make sure this is consistent with 3.6?
(Please see answer above to 3.6 for corrections)

4.6. 2 years does not seem enough, especially if you are planning to publish a paper after your dissertation.

After completion of the research, the transcribed data (not including any identifying data, such as participant names, and identifying references) will be retained for 3 years, on a password-protected laptop within the researcher's home, which only the researcher and their supervisor will have access to.

Participant invitation letter. Please, clarify what is a safe and private space.

. As the interviews will take place remotely, it will be important for you to be in a safe, and private space if possible, i.e. whereby you are able to talk freely and cannot be overheard due to the sensitive nature of the interviews

You taking part will be safe and confidential. You repeat some information here.
The repeated information has been deleted.

Risk-assessment is for research off-campus. I understand your interviews are online. Could you please check this?

Because of ambiguity concerning the meaning of "off campus" in relation to online data collection it was decided to complete a risk assessment to cover any potential risks.

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

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

Student's name *(Typed name to act as signature):* Shrina Patel
Student number: U1826624

Date: 29.06.2020

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

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

[ ] HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

[ ] MEDIUM (Please approve but with appropriate recommendations)

[x] LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: **Andrea Giraldez-Hayes**

Date: 11/06/2020

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research 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 Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

6.5. Appendix 5 - Participant information sheet

PARTICIPANT INVITATION LETTER

Title of the Study: Sickle Cell Disease in young men, and its impact on relationships

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully. Feel free to ask any questions you may have.

Who is carrying out this research?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Professional Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I am conducting research into young men's experience of having Sickle Cell Disease (SCD), and how this impacts on their romantic relationships. Most research within SCD focuses on medical management, despite its impact on quality of life. Support through interpersonal relationships has been seen as an important factor for well-being, however one type of relationship that is under-researched is romantic relationships. Men and women have different experiences of these relationships but no research to date has explored how young men with SCD navigate romantic relationships. Therefore, this research is being carried out to do this, with the aim of gaining a better understanding of how young men with SCD experience relationships, and to provide guidance on what kind of support, if any, may helpful to them.

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 is invited to take part?

I am looking to invite any individual who identifies as a man, diagnosed with SCD, and is between the ages of 18-35 years-old, is English-speaking, and lives in the United Kingdom.

I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect at all times.

Participation is completely voluntary, and you are free to decide whether or not you would like to take part.

What will your participation involve?

If you agree to participate you will be asked to:

- Participate at an agreed date and time in an hour-long individual interview via video or audio call on Microsoft Teams. However, I am asking for an hour and a half of your time, to allow for questions before and after the interview.
- As the interviews will take place remotely, it will be important for you to be in a safe, and private space if possible i.e. somewhere you are able to talk freely and cannot be

overheard due to the sensitive nature of the interviews.

- Interviews will be similar to having an informal chat, with a few, set, structured questions to potentially guide the interview. Questions asked will be around your experience as a man living with SCD, and how this impacts on your romantic relationships. You do not have to answer all questions asked, and can stop participating at any time.
- The interview will be audio-recorded (with your consent) on Microsoft Teams, and an audio-recording device (for back-up), in order for the data to be analysed as accurately as possible. The researcher will be the only person who will have a copy of the recording.
- Before participating, informed consent will be required from you, through signing the consent form via email.
- To thank you for your time and input in participating, you will receive a £10 Amazon voucher at the end of the interview via email and also be entered into a prize draw of a £100 Amazon voucher. Your participation will also be really valuable in helping to develop knowledge and understanding of this research topic.

Your taking part will be safe and confidential

- The audio-recordings will be transcribed following the interview. You will not be identified by name in the transcript, or within any of the write-up of the research. To protect your identity in this way, an ID number will be allocated to you, and a fake name will be used instead of your real name within the transcript and write-up of the research. Quotes from the interviews may be used in the write-up of the research but will be anonymised. Any potentially identifying information will be removed from the transcript and write-up of the research. In addition to the researcher, the supervisor may review the anonymised transcript, however they will also be bound by the agreement to keep the information confidential.
- The only time confidentiality will need to be broken is if the researcher has concerns around your safety, or the safety of anyone else.
- Although this research is not anticipated to cause discomfort or distress, some of the questions asked in the interview may result in some emotional distress. Care will be taken to conduct the interview in a sensitive manner, and safety measures will be in place for any potential distress experienced, both throughout the interview, and after. Steps to carry out in the event of this occurring will be discussed between the researcher and yourself before the interview begins. You will also be given space at the end of the interview to ask any questions and raise any concerns you may have. There are also services that will be provided, that can be contacted should you need support after the interview has been completed.

What will happen to the information that you provide?

- The information you provide will be securely stored on a password protected computer, or encrypted storage device.
- After the study has been completed, audio-recordings of the interview, and any identifying information such as your name and contact details, and any identifying references, will all be destroyed. However, anonymised interview transcripts may be kept for up to 3 years after the research is completed on a secure-server, on a password-protected computer, which only the researcher and supervisor will have access to. This is due to the possibility of developing the research for publication in academic journals/sharing the research to organisations such as the Sickle Cell NHS services / charities.
- You will be given a brief summary of the findings at the end of the study if you would like.

What if you want to withdraw?

Participation is completely voluntary. You are free to withdraw and not continue with the research study at any time without explanation, disadvantage or consequence.
You may also request to withdraw your interview data even after you have participated, 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, and the researcher would reserve the right to use the anonymised material that has been provided).

Contact Details

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

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

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

6.6. Appendix 6 - Consent form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of the Study: Sickle Cell Disease in young men, and its impact on relationships

Upon agreeing to participate, please read through the statements below, signing each with your initials, to confirm your understanding of what is involved in the study, and approving your consent to participate.

Initials:

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. I have been informed that the only time confidentiality will need to be broken is if the research has concerns around my safety, or the safety of anyone else. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐

I understand my interview will be audio-recorded for the purposes of transcription and that the recording will be deleted once the study is complete. I also understand that anonymised quotes may be used in the write-up of this research, i.e. for publication. ☐

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun. ☐

I hereby freely and fully consent to participate in the study, which has been fully explained to me. ☐

Participant's Name (BLOCK CAPITALS)

……

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..……

6.7. Appendix 7 - Debrief form

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on exploring how young men experience their Sickle Cell Disease, and its impact on their relationships. Your time and input is greatly valued.

This letter has some information that may be useful for you now that you have taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

- The information you have provided will be securely stored on a password protected computer, or encrypted storage device.
- Your name, and any other potentially identifying information you mention, will be changed in the written transcript, and in the write-up of the research. Quotes from the interviews may be used in the write-up of the research but will be anonymised.
- After the study has been completed, audio-recordings of the interview, and any identifying information such as your name and contact details, and any identifying references, will all be destroyed. However anonymised interview transcripts may be kept for up to 3 years after the research is completed on a secure-server, on a password-protected computer, which only the researcher and supervisor will have access to. This is due to the possibility of developing the research for publication in academic journals / sharing the research to organisations such as Sickle Cell NHS services / charities.
- You can be given a brief summary of findings once the study is completed. If you would like to receive this please notify the researcher using the email address above.
- You have the right to withdraw your interview data from the study without disadvantage and without being obliged to give any reason. However, you must notify the researcher of your request to withdraw your data, 3 weeks from the date of taking part in the study. After 3 weeks, the researcher reserves the right to use your anonymous data as analysis of the data would have begun.

What if you have been adversely affected by taking part?

It is not expected that you will have been negatively affected by taking part in the research, however, if you do feel that your participation (or its after-effects) may have been challenging, distressing or uncomfortable in some way, you may find the following resources/services helpful for receiving information and support:

1) Sickle Cell Society helpline service: 02089637794 | helpline@sicklecellsociety.org. | https://www.sicklecellsociety.org/helpline/ | (10am-5pm Monday-Friday) | In writing: Helpline Service Team, Sickle Cell Society, 54 Station Road, London NW10 4UA
2) Samaritans for distress/despair 24-hour helpline: 116123 | www.samaritans.org
3) Mind – Mental Health problems: 03001233393 | www.mind.org.uk | (Monday-Friday 9am-6pm)
4) Rethink Mental Illness: 03005000927 | www.rethink.org | (Monday-Friday 9.30am-4pm)
5) SANEline emotional support, information, and guidance: 03003047000 | www.sane.org.uk/support | (daily 4.30pm-10.30pm) | peer support forum: www.sane.org.uk/supportforum
6) RELATE for relationship support: www.relate.org.uk

7) CALM (Campaign Against Living Miserably, for men aged 15-35): 0800585858 | www.thecalmzone.net | (5pm- midnight daily)
8) Men's Health Forum 24/7 stress support for men: www.menshealthforum.org.uk

You are also very welcome to contact the researcher, or the research's supervisor if you have specific questions or concerns.

Contact Details

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

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

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

6.8. Appendix 8 - Recruitment poster

6.9. Appendix 9 - Interview Guide

Thank you for taking the time to speak with me today. I will ask you a few different questions about how your Sickle Cell condition affects you, and how this effects your romantic relationships. If at any point you feel like you need to stop, please do let me know.

1) Can you tell me a bit about what it's like living with Sickle Cell and how it affects you?

2) How does Sickle Cell affect your romantic relationships?
    a. *PROMPT*: If in a current relationship - How its affects the relationship / disclosure to partner / partner choice? / how it affected past relationships
    b. *PROMPT*: If not in a relationship – How it affects dating or partner choice (and disclosure to them)/ views on future relationships / how it affected past relationships

3) Do you think there are general expectations of how men should be in a relationship? (generally, regardless of sickle cell)
    a. *F/U*: is this how your culture / community perceive males or just society in general?
    b .*F/U*: Do you think your condition has effected this (how as a man you are perceived / are in a relationship)

4) Following this, does this effect how you perceive yourself / expectations of yourself in a relationship?
    a. *F/U*: do you think these views/expectation of yourself would be different if you did not have sickle cell?

5) Has COVID-19/ the current pandemic impacted on how SCD has affected your relationships / view on relationships?

6) Thinking about intimate aspects of your relationship, has having Sickle Cell effected this in any way? (*Prompt:* sexual difficulties e.g. priapism)

7) Considering all you've told me today, is there anything you feel that healthcare professionals should be made more aware of, or can do to support with these kinds of difficulties you have discussed today?

8) Is there anything else you would like to say, or you think is important for me to know about how your Sickle Cell affects your romantic relationships?

Prompts:

- Tell me more about X

- 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

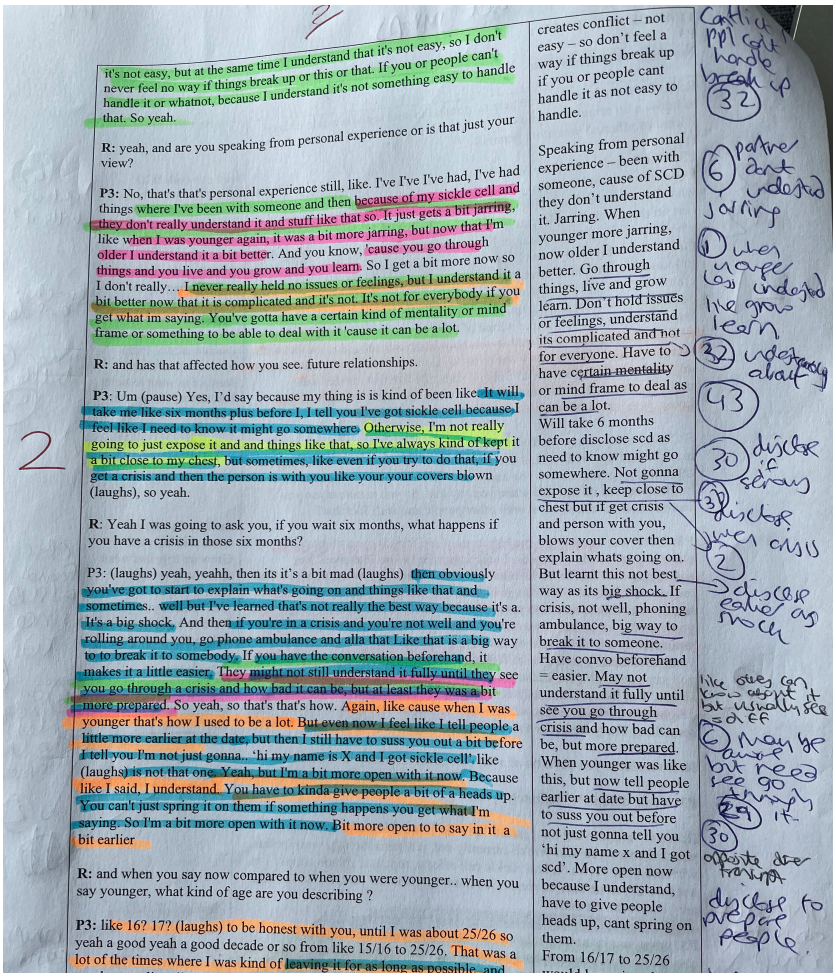
6.10. Appendix 10 – Presentation/Transcription key

Minor changes have been made to the interview transcript extracts within the results chapter for presentation and readability purposes.
Superfluous words which do not add to meaning of the extracts have been omitted to shorten quotes and this is represented by a dotted line in between rounded brackets; **(…)**
To offer further explanation to the reader for sentences which rely, and are relevant to previous utterances, this has been shown by adding context to the quote in italics within squared brackets; **[*example]***
Pauses are depicted by dotted lines; **…**
Filler words such as repetitions i.e. words such as 'like' or 'you know' have been removed for clarity.
To maintain confidentiality and anonymity, pseudonym names have been used, and locations have been replaced with more broader areas.

6.11. Appendix 11a - Transcripts with initial notes on the side margins

Researcher: So I guess a good place to start 'cause I know everyone experiences Sickle Cell really differently, uhm can you tell me a bit about what it's like living with sickle cell for you and how it effects you?	
P1: Yeah, sure, uhmm. I guess it's always been something that I used to keep quiet about. Um, as a child so like 'cause no one else really experienced what I was experiencing. Like I'd just be in pain random. Well, what felt like random I just be in pain and uhm you know explaining it to your friends and say oh I just got a tummy ache or my leg hurts kind of thing uhm so it was difficult to kind of speak about it and talk about it and uhm when I was younger then I think I got to like University uhm and then I began to speak about it a bit more 'cause it was a bit more. I think peop.. 'cause I did a science degree as well, so people kind of knew a little bit more about it. So sort of started to open up and stuff like that. Uhm But I do think it was always something that I kept quiet uhm and being… when I was younger I didn't know that what was my triggers or anything like that. So I used to associate it with like 'Oh, it's because I'm excited or something or because uhm I've run around a lot or something or I'm just tired so that I'm in this pain, but I didn't really understand until I got much older	used to keep quiet no one else experienced random pain explaining/lying to friends difficult to speak about open up at uni as people knew more kept quiet about mistaken triggers when younger didn't understand till older
Researcher: Ah so you knew you had SCD and were trying to figure out what caused the pain, what your triggers were?	
P1: Yeah, yeah. So I knew I had it, uhm mainly because uhm as a child, you have like checkups with your uhm paediatrician every I cant remember, every, is it every six months or something like that. So I used to go to the pediatrician and they would explain things and you know give me different medications, and I had to take penicillin every day, so just things like that. That kind of made me aware that OK, cool I have the condition Sickle Cell but it didn't really help with understanding what it was because as a child you kind of want to be included in everything uhm, so you kind of go against like I'll make sure you're wrapped up warm, oh theres snow outside, let me go outside and things like that. So I think that experience kind of comes with age uhm in terms of getting to understand how to manage your sickle cell, so I guess now, uhm, I'm more, I'm a lot more aware. I do so one of my I think one of my triggers are like cold weather, stress, uhm and just doing too much. So I started to get a grasp of that. So stress unfortunately I cant you know, life is stressful (laughs). But uhm but like I think, uhm I managed that quite well. I just try to rest as much as I can, and doing too much…I'm getting better at it, but there are times I slip up and then when I do slip up, its like abh damn like I could have prevented that. Uhm, but yeah, that's kind of how I feel, but other than that, I do try to, you know, like be as normal as possible and just do what I wanna do.	Aware of condition Paediatrician check-ups and gave meds. But no understanding of what it was so go against advise to feel included when child Managing SCD comes with age more aware of triggers Cold weather / doing too much / stress Try to rest When slip up, could have prevented Try to be normal as poss and do what I want to do
Researcher: And when you said um, when you were younger, you felt like you wanted to go and play in the snow and do things, even though maybe you shouldn't have done them 'cause they were triggers, what age do you feel like that changed from going from that to actually understanding your triggers, kind of maybe looking after yourself a bit more or being more aware of your triggers?	
P1: mmm I probably say it changed in (pause) secondary school and mainly because it was sort of like I would go to trips and get a crisis, for example. Uhm in year X (*early secondary school*) I went to (*somewhere in Europe*) and because of like all the walking around and like the rain and everything like that it just wasn't great conditions all of sudden got crisis in my leg and in (*somewhere in Europe*) they didn't understand that I had sickle cell so they gave me a cast on my leg. They thought it was a umm it was fractured so they thought it was a hairline fracture so there was that. And then I had like a exchange trip to (*another destination in Europe*) when I was I think that I was in.. that might have been. It was ten years ago, so I was 17. I had an exchange trip to X and then again I was out late drinking and it was cold, um so then it felt like I had uhm, so one of my friends was like ah it was probably kidney stones or something. I was like no its like sickle cell or whatever. But then when I went to hospital eventually they didn't understand either. So they	Secondary school – go on trips get crisis Walking and rain – crisis in leg In X hosp, didn't understand SCD – gave wrong treatment Drinking and cold – friend thought kidney stones X hospital didn't understand SCD – gave

6.12. Appendix 11b - Handwritten codes on the side margins



6.13. Appendix 11c - Microsoft excel codes in relatable groups

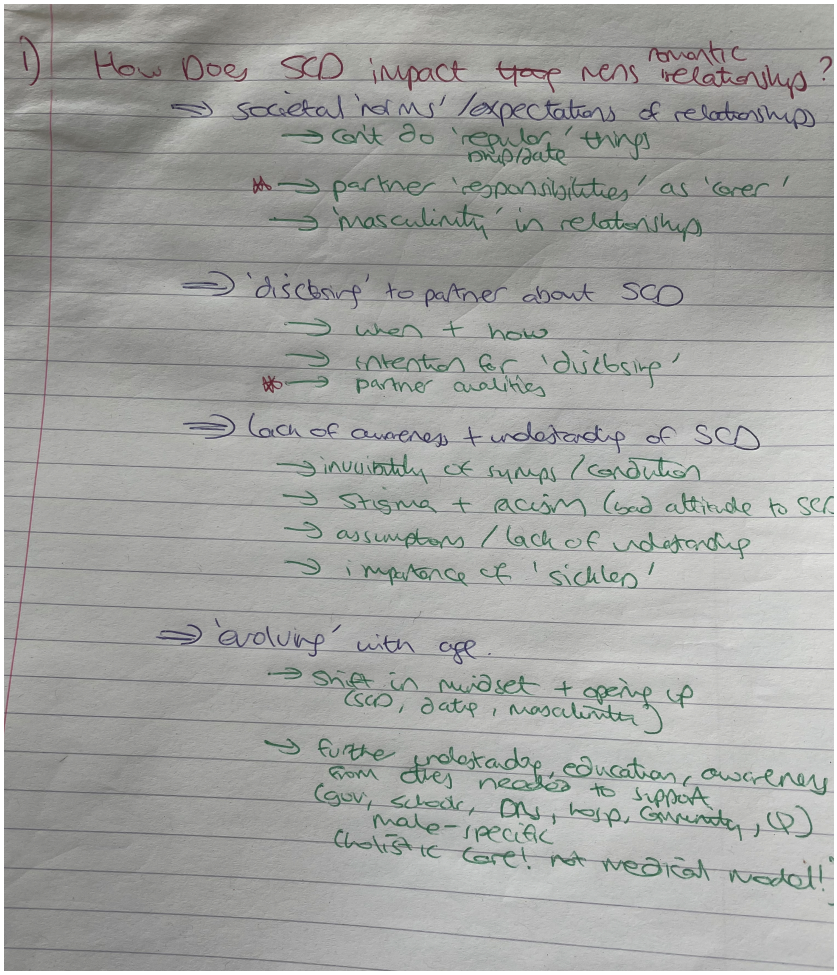
	A
1	Initial Codes
2	28) near death experiences due to scd (or death of loved one from scd)
3	scd = draining, tiring, mentally, physically, emotionally, damp in my spirit, something have to live with
4	48) want to feel normal / go against advice to feel included - scd in way of engaging with people
5	unpredictability of crisis (effect rship) and in and out of hosp - BUT p4 said scd don't effected rships or social life that much
6	44) cant do regular things in rships - go out - cancel plans - cant impress partner - extra thinking and planning
7	SCD as an extra thing to consider when dating
8	31) partner stuck through / caring / understanding - 2 don't mind no understnading if willing to learn / been learning process for partners
9	32) when see me in bad state, partner scared off - few rship ended (cant take it)- their choice effects mentally so see it as it is what it is - unpredictable scd so rships complicated - take out of me and partner comfort zone
10	40) partner worried / assumes worst / panic with my scd - reminds me of my reality - partner worry more than friends etc - her journey too - carer so responsibility
11	14) partner aware, despite hiding symps of SCD
12	27) ask partner how feel to be with someone with SCD / carer concerns
13	35) importance being on same team and comprimise (like 20)
14	16) don't want to be burden to partner / have to be my carer - linked to feeling like a burden when child on parents
15	23a) covid not effected
16	23b) covid - made me realise what I want - focused me - not settling rslp
17	24c) covid - cant see women - had fomo - scared to go out
18	23d) covid cant go out with partner or dress up / go hols
19	23e) covid puts everyone same playing field
20	25) sex causes crisis
21	26a) not effected intimately apart from sex - love lang phys touch, like massage
22	26b) intimately effects tiredness/fatigue
23	30a) no priapism (pray never have) (touch wood thank not)
24	30b) has priapism didn't know scd related, DR mistreated
25	30a) importance of wanting to start disclosing got SCD earlier when dating / not find out when have crisis to prepare / inform partner what in for / now part of me (combined with evolve rship? 1)
26	30b) only disclose at start of dating if know will be serious, easier to walk away when early,partners can walk away(unless got kids), friends and fam would never (problems disclosing late)- if not serious cba to explain SCD(people use aj
27	30c) 4) disclose straight away - diff ways to disclose
28	SAID I 8a) dating others with trait - complicates as don't want child with SCD so have to end rship (dissapointing if liked partner) - one partner had baby with partner with trait and had treatment in place (mix with 30b)
29	8b) wouldn't advocate to not date anyone just cause have trait (but one participant still wonder if bad decision)
30	3) thinking about dating others with trait important decisions - consider other options eg IVF
31	guilty if have child with SCD or cruel
32	may change mind in future about halving kids with trait - easier said than done (not be someone with trait)
33	don't disclose early due to stigma and assumptions or lack of knowledge myself
34	22) despite SCD appreciate / gratitutde
35	positive mindset
36	21) without SCD less quiet/reserved / - made me go into myself and be more cautious / more masculine / more hobbies (can effect rship link?) - overall diff - be more confident
37	2) SCD kept quiet/ hidden / lied - due to lack of understanding and difficult to speak about and to avoid being burden and masculinity and to avoid inpatient stay (linked to 6)
38	29) invisibility of symptoms (not sure to 2)
39	10) what men should do by society 'provide, pay bills, work hard, be strong, get money' - causes crisis - hard to keep up with SCD - guys don't speak about it or go therapy - and what females expect of men
40	11) although society puts this pressure / 'old school way', its my beliefs of how men should be too (dueto culture growing up in fam or culture)
41	SCD and men = double whammy
42	45) when dating - ask what job do / what car drive
43	15) perception see me as weak, less of a man , in a state, inferior - pity (two participant 6 and 7 said opposite perception) see me strong like warrior
44	17) girls show pain I wouldn't - feminine - liked to be looked after
45	43) internal struggles/ mentality (due to pressure, conform to masculinity norms despite worsening SCD -prove self - but now put self first EVOLVE, understand limits)
46	19) what men should do by culture / some don't listen to it though
47	42) ' deal with it ' 'get on with it' ; man up' - overcome on own
48	self manage
49	I like to help others, don't like people helping me / worory about others health, note own
50	20) more westernised now - equality and joint effort in partnerships (like 35)
51	5a) stigma of scd
52	5b) assumptions of scd
53	6a) no understnading of SCD from self when younger, or friends, or others, or DRs (intellectualise and/or racism = wrong treatment) , AND partners - bad attitude to SCD
54	6b) bad attitude to SCD by others eg government
55	9) don't blame parents (Some parents been v supportive - fam shielded me may be thats why look for supportive partner),also less knowledge/awareness then - have convo about it as might effect future rship - interesting didn't effect
56	more awareness now
57	1a) evolved - as grew older opened up more about SCD due to better understnading and management/control of SCD - journey - realised effect those around me too - opening up helps
58	1b) with dating opened up more with partner, with age evolved or disclosed earlier , maybe want to settle down - or evolved in dating journey
59	1c) with 'masculinity norms' evolved over age got older, realised toxic
60	7) speak up to change assumptions / increase awareness
61	schools do more to educate - having kids if partner has trait, blood donation, priapism, got scd - lots of closed doors have to barge open (lack of opportunity with SCD) - due to lack understanding? / awareness? AND 46 more research f
62	DR talking about fam planning when young, weird but needed - DR talk about it earlier
63	DRs intellectualise, but don't have knowledge from experience
64	need protocols in hosp
65	nurses as hosp good as more holistic care
66	need more qualified specialists in niche area of scd, psych, hcp etc
67	38) integrate psych in SCD services and critical periods eg crisis, and also post recovery - (refer to psych not jus phys health) child psych important to unpack things - feel diff at school - and unpack masculinity stuff too and check in with
68	not just physical mental health too - normalise therapy
69	more support (in community) - male specific - outreach services - 2 tier hosp and community suppn
70	47) don't understand unless go through yourself - importance of talking to other sickles
71	
72	
73	KEY:
74	NOT SURE WHERE TO PUT
75	HOW SCD EFFECTS RSHIPS
76	DUE TO 'HEGEMONIC MASCULINITY' + STIGMA AND ASSUMPTIONS OF SCD + LACK OF UNDERSTANDING AND AWARENESS OF SCD
77	EVOLVED WITH AGE SO SCD IMPACTS LESS ON LIFE AND RSHIPS NOW - NEED TO RAISE AWARENESS + UNDERSTANDING + SUPPORT THROUGH GOV / HCP / PSYCHOLOGY
78	

6.14. Appendix 11d - Codes linked to participant and transcript page numbers and line numbers

nitial Codes	P1	P2	P3	P4	P5	P6	P7
28) near death experiences due to scd (or death of loved one from scd)	17	1	10	9	1, 13	8, 9	6, 9
scd = draining, tiring, mentally, physically, emotionally, damp in my spirit, something have to live with							1
48) want to feel normal / go against advice to feel included - scd in way of engaging with people	1, 5, 18			1, 3, 9,10	1, 6		
unpredictability of crisis (effect rship) and in and out of hosp - BUT p4 said scd don't effected rships or social life that much	3		1	1,9		1	4, 7
44) cant do regular things in rships - go out - cancel plans - cant impress partner - extra thinking and planning			4,12	3	6, 7		1, 2
SCD as an extra thing to consider when dating	4, 5						
31) partner stuck through / caring / understanding - 2 don't mind no understnading if willing to learn / been learning process for partners		3,4, 13	4, 12	4, 6, 10	4, 6, 9	1, 2, 3, 4, 5, 6, 8 , 9	3, 4, 8
32) when see me in bad state, partner scared off - few rhsip ended (cant take it)- their choice effects mentally so see it as it is what it is - unpredictable scd so rships complicated - take out of me and partner comfort zone		3, 5 , 6	1, 2, 3,4	2, 4 , 5	6	2, 3, 9	1, 3, 4, 8
40) partner worried / assumes worst / panic with my scd - reminds me of my reality - partner worry more than friends etc - her journey too - carer so responsibility		15	3, 4				
14) partner aware, despite hiding symps of SCD	9						
27) ask partner how feel to be with someone with SCD / carer concerns	14	13, 14				8	1
35) importance being on same team and comprimise (like 20)		5, 8 , 9 , 15		10	4, 6	1	1, 3
16) don't want to be burden to partner / have to be my carer - linked to feeling like a burden when child on parents	10, 11			5, 9	4, 7, 9		1, 3, 4
23a) covid not effected				9			
23b) covid - made me realise what I want - focused me - not settling rsip	12, 13		11			7	8
24c) covid - cant see women - had fomo - scared to go out	13				8		7
23d) covid cant go out with partner or dress up / go hols		9		10		9	
23e) covid puts everyone same playing field			11				
25) sex causes crisis	14			4	8		8
26a) not effected intimately apart from sex - love lang phys touch, like massage	14	10					8
26b) intimately effects tiredness/fatigue			12	4	7, 8	1, 4, 9	
36a) no priapism (pray never have) (touch wood thank not)	14 (self disclosed)		13 (I asked)	4 (self disclosed)			8 (I bought up)
36b) has pripaisim didn't know scd related, DR mistreated		10 (I had to ask), 11			8 (I had to ask)	1 (self disclosed), 4	
30a) importance of wanting to start disclosing got SCD earlier when dating / not find out when have crisis to prepare / inform partner what in for / now part of me (combined with evolve rship? 1)	3, 4, 7, 16		2, 17	13		3	3
30b) only disclose at start of dating if know will be serious, easier to walk away when early,partners can walk away(unless got kids), friends and fam would never (problems disclosing late)- if not serious cba to explain SCD(people use a	3, 5, 6	2, 3 , 6	2, 5 , 8	13	2, 5		
30c) 4) disclose straight away - diff ways to disclose	4	5, 12	2	6		2	3
AID I 8a) dating others with trait - complicates as don't want child with SCD so have to end rship (dissapointing if liked partner) - one partner had baby with partner with trait and had treatment in place (mix with 30b)	3, 4 , 5, 6	4, 5	5, 6	6, 7	2, 4, 7	3,4	2
8b) wouldn't advocate to not date anyone just cause have trait (but one participant still wonder if bad decision)						3	2
3) thinking about dating others with trait important decisions - consider other options eg IVF	3, 4, 5, 6, 7				2, 5	3	
guilty if have child with SCD or cruel	6	4	6	6	2		2
may change mind in future about haivng kids with trait - easier said than done (not be someone with trait)	6		17	7	4		2
don't disclose early due to stigma and assumptions or lack of knowledge myself	6		2		3	2	
22) despite SCD appreciate / gratitutde	6, 7, 12, 13, 15	14	10, 11	2, 8, 9, 10	1	5, 7, 8	
positive mindset	13	4			5	7, 8	
21) without SCD less quiet/reserved / - made me go into myself and be more cautious / more masculine / more hobbies (can effect rship link?) - overall diff - be more confident	11, 12		1, 11	9	6, 7	4	1, 6, 7
2) SCD kept quiet/ hidden / lied - due to lack of understanding and difficult to speak about and to avoid being burden and masculinity and to avoid inpatient stay (linked to 6)	1, 2, 7 , 9 , 10 , 14, 15	15	1,2 , 3, 4, 5, 8 , 10	4, 5, 6, 8	3, 4, 9	2, 3, 4, 5,6, 7, 8, 10	6, 9
29) invisibility of symptoms (put next to 2)	2	2, 3	2, 13	3, 4 , 5, 13	6, 9	7	9
10) what men should do by society 'provide, pay bills, work hard, be strong, get money' - causes crisis - hard to keep up with SCD - guys don't speak about it or go therapy - and what females expect of men	8, 9 , 11	7,8, 13	6, 7, 14	4, 7, 8	1, 4, 5 , 7, 10, 12	4, 5 , 6	1, 4, 5, 6, 7
11) although society puts this pressure / 'old school way', its my beliefs of how men should be too (dueto culture growing up in fam or culture)	8, 18	7,8	6, 7	7	2		
SCD and men = double whammy						7	5
45) when dating - ask what job do / what car drive			9				6, 7
15) perception see me as weak, less of a man , in a state, inferior - pity (two participant 6 and 7 said opposite perception) see me strong like warrior	6, 10		3,4 , 5 , 6, 7, 9 ,13, 14	5, 8	3, 4, 5, 7, 9	6,7	6
17) girls show pain I wouldn't - feminine - liked to be looked after	10, 11						
43) internal struggles/ mentality (due to pressure, conform to masculinity norms despite worsening SCD -prove self - but now put self first EVOLVE, understand limits)	3, 6, 8, 9		1, 2, 5 , 6, 7, 8 , 10 , 12, 13, 14	4, 5 ,	3, 4	5, 6 , 8	5
19) what men should do by culture / some don't listen to it though	11	7	7	7	4, 5, 12	6, 10	5
42) ' deal with it ' 'get on with it' ; man up' - overcome on own		6	1	4,8		4,5 , 6	
self manage					9	7	1
I like to help others, don't like people helping me / worory about others health, note own	11		10	8			1, 2, 4
20) more westernised now - equality and joint effort in partnerships (like 35)	11	7,8, 9		10			
5a) stigma of scd	5, 6		5	6		3,5 , 6 , 8,9, 10	9
5b) assumptions of scd	2,4, 5, 6	2, 4	8	10	3	2, 3	
6a) no understnading of SCD from self when younger, or friends, or others, or DRs (intellectualise and/or racism = wrong treatment) , AND partners - bad attitude to SCD	1, 2, 5, 16, 17	1, 2, 4, 10, 11, 12	1, 2,4, 5, 7 , 8 ,9, 13, 17	2, 3, 6 , 8,10, 13	3, 4, 9, 10, 11, ,12	1, 2, 4, 5, 6, 7,9, 11, 12, 13	1, 3, 8, 9, 11
6b) bad attitude to SCD by others eg government	13, 14, 16	12				10	
9) don't blame parents (Some parents been v supportivE - fam shielded *me may be thats why look for supportive partner*),also less knowledge/awareness then - have convo about it as might effect future rhsip - *interesting didn't effect*	6, 7	12	13	1, 9, 11	8	10	
more awareness now			14		3, 12		3
1a) evolved - as grew older opened up more about SCD due to better understnading and management/control of SCD - journey - realised effect those around me too - opening up helps	1,2, 12, 16	6	2, 3, 7, 8 , 9, 10	2, 3, 4 , 5, 6	1	1, 2, 4, 5, 6 , 7, 8, 9	10
1b) with dating opened up more with partner, with age evolved or disclosed earlier , maybe want to settle down - or evolved in dating journey	3, 4, 7, 14, 15	6	2, 3, 4, 5, 12, 17	4, 5 , 6, 13	9	2, 4, 5, 6	
1c) with 'masculinity norms' evolved over age got older, realised toxic	8, 9		7, 9, 12		3	6, 7, 8	
7) speak up to change assumptions / increase awareness	5, 16			6, 10, 13	1, 5	3, 5, 7, 8	
schools do more to educate - having kids if partner has trait, blood donation, priapism, got scd - lots of closed doors have to barge open (lack of opportunity with SCD) - due to lack understanding? / awareness? AND 46 more research f	16	12, 13, 14	15			10, 14	
DR talking about fam planning when young, weird but needed - DR talk about it earlier	16, 17						
DRs intellectualise, but don't have knowledge from experience					10	11, 12	
need protocols in hosp						12, 13	
nurses as hosp good as more holistic care				12	11		
need more qualified specialists in niche area of scd, psych, hcp etc						13	11
38) integrate psych in SCD services and critical periods eg crisis, and also post recovery - (refer to psych not jus phys health) child psych important to unpack things - feel diff at school - and unpack masculinity stuff too and check in with	9, 10, 15, 18, 19	13, 14	1, 15, 16, 17	12	10, 11, 12	14	10, 11
not just physical mental health too - normalise therapy		13				1, 9, 14	1, 2
more support (in community) - male specific - outreach services - 2 tier hosp and community suppn				12	11	12, 13	11
47) don't understand unless go through yourself - importance of talking to other sicklers			1, 15, 16	4, 11, 13	10, 13	5, 8, 11, 12, 13	11, 12

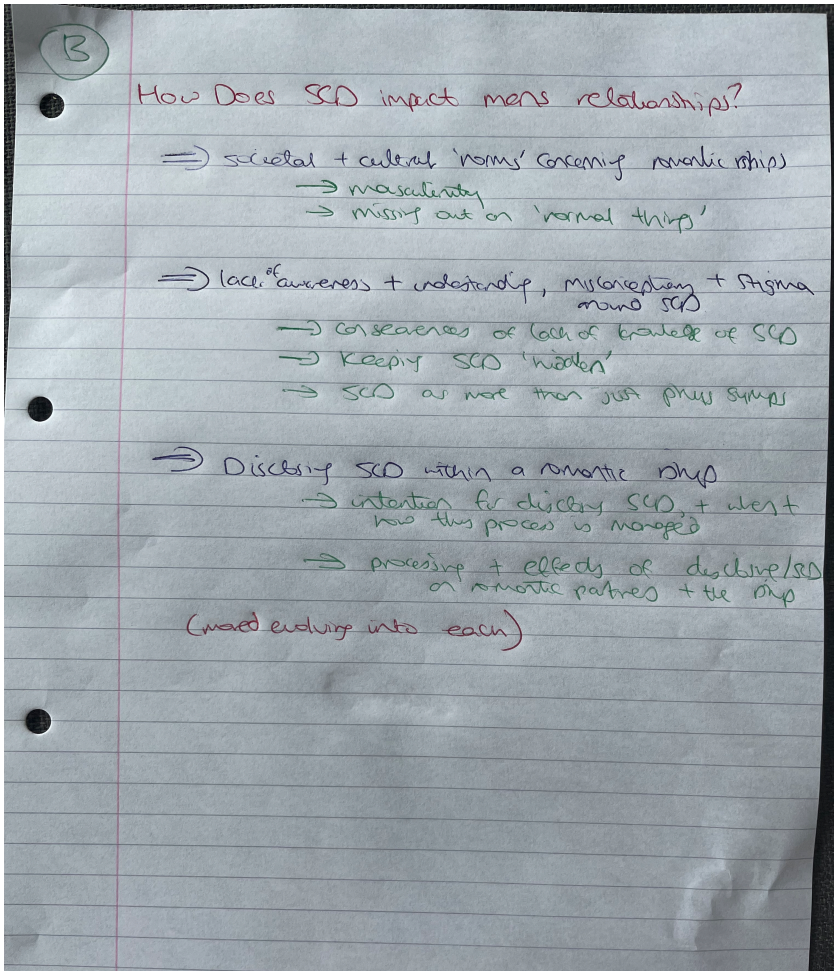
6.15. Appendix 11e – Visual mind-map to sort codes

6.16. Appendix 11f - Original 9 themes and subthemes



6.17. Appendix 11g – Broader themes and subthemes

6.18. Appendix 11h - Final themes and subthemes



6.19. Appendix 12 – Reflective diary inserts

RECRUITMENT

- whilst recruiting, and advertising, women with SCD offered to share my research a lot more compared to men. Women also contacted me to ask more about the research, whereas men had to be direct messaged by me to invite them to participate in the research. Although this shows a lack of men coming forward for research / having an online presence, and thus the need to raise mens voices to gain insight into how SCD impacts them, it also shows more research on females is needed too. Although for general SCD research, there is more research conducted on women, for romantic rships specifically, and in the UK, there isn't. ….
- What will make it a safe space for men to come forward? Is it only 'masculinity' norms preventing this i.e. not talking about emotions / how you feel / opening up? - PPI thought that I would have no trouble recruiting men but I did – should I have applied for NHS ethics and potentially would have gained a bigger sample? …is romantic relationships too personal a topic to come forward for? Stigma? Shame? Embarrassment? …Sometimes men would email me back showing interest in the research, but then ignore further emails. I wondered what made them want to decide to not take part anymore (I assume), were they just busy, or did they change their mind and were not interested anymore? Was there a lot of paperwork they had to complete and did not have time to go through it? i.e. was there too many back-and-forth parts before the actual interview; screening process, consent, participant information etc?

INTERVIEWS

- one participant had children with SCD, and I was conscious all previous participants had spoke about not wanting children with SCD. I was taken by surprise, and this may have impacted how much further I probed for his opinions / thoughts, as I did not want to make any potential assumptions or offensive comments based on previous data I had gathered from other participants?"
- one participant expressed his mother had passed away from SCD and was currently experiencing 'bad mental health'. This made me more conscious of asking certain questions as I did not want to trigger further low emotions

WRITE UP

- so difficult to fit everything into the constraints of a doctoral thesis. Although this research explores findings from a more broad research question on how SCD impacts romantic-relationships for men, I would hope future literature may identify certain aspects from this research and look further into these topics for more precise and detailed findings, and understanding. This is only starting the conversation, much more needs to be done.