



CREATE

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

<http://create.canterbury.ac.uk>

Copyright © and Moral Rights for this thesis are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given e.g. Newsome, Dominique (2016) My story, my identity and my relationship with work: sickle cell disorder. D.Clin.Psych. thesis, Canterbury Christ Church University.

Contact: create.library@canterbury.ac.uk



Dominique Newsome BSc Hons MSc

MY STORY, MY IDENTITY AND MY RELATIONSHIP WITH WORK:
SICKLE CELL DISORDER

Section A:
Identity Construction in People Living with Sickle Cell Disorders
Word Count: 7,771 (230)

Section B:
Narratives of the Construction of Work identity in People Living with Sickle
Cell Disorder
Word Count: 8,000 (346)

Overall Word Count: 15,771 (16,347)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2016

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I am so grateful to all the participants; without them this would not have been possible.

I would like to thank my manager, Dr Rachel Terry and the library staff whose encouragement is beyond what I could have asked. Special thanks to my inspirational supervisors, Dr Helen Ellis- Caird and Dr Nicky Thomas for their guidance and sharing their experience.

Lastly, a big thank you for my Mum and Dad, I am forever indebted to you. My Mom for inspiring me to persevere. Most importantly, I acknowledge my work could neither have been commenced nor completed without the love of my incredible husband.

Summary of MRP Portfolio

Section A is a literature review critically evaluating research related to the construction of identity in people living with sickle cell disorder. 12 peer reviewed papers were identified and the results were synthesised to explore identity construction across the lifespan focusing specifically on individuals living with sickle cell disorder self-perception and social- perception. Gaps in the existing evidence were discussed particularly the lack of research related to the achievement of generativity in adulthood. Clinical and research implications are also discussed.

Section B presents a Narrative Analysis of the experience of developing a work identity in people living with sickle cell disorder. The analysis revealed that participants struggled to align their sick identity with the values of the wider organisation. A battle with maintaining power was a core narrative and participants' relationship with their sickle cell disorder was influential in their resilience to their experiences. Implications for clinical practice and research are discussed.

Section C is an appendix of supporting material. This includes: search strategy, study quality checklist and a summary of the articles for Section A; the measures and information administered as part of the research study, submission guidelines for the journal for which Section B is intended, an example interview transcript and the author's reflections.

Contents

Section A: How is identity constructed in people living with sickle cell

disorder?	9
Abstract	10
1. Introduction	11
1.1. What is sickle cell disorder (SCD)?	11
1.2. Identity development	12
1.2.1. Erikson's Theory	13
1.2.2. Marcia's model	15
1.2.3. Racial identity	15
1.2.4. Perception of others in identity development	17
1.2.5. Stigma	18
1.3. Summary and aims of the review	19
1.3.1. Key terms	20
2. Methodology	20
2.1. Search procedures	20
2.2. Inclusion/ exclusion criteria	21
2.3. Search results	21
2.4. Structure of review	25
3. Main body of review	25
3.1. Identity construction and self- perception	25
3.1.1. The impact of SCD on identity development	25
3.1.2. The impact of identity development on symptoms of SCD	28
3.1.3. The impact of racial identity on symptoms of SCD and quality of life (QOL)	29
3.2. Influence of perceptions of others on identity development	32
3.2.1. The impact of school experience/ disclosure on identity development	32
3.2.2. The impact of parenting and families on positive identity development	34
3.2.3. The impact of stigma on identity development	35
3.2.4. The impact of others perception of race on SCD identity	37

4. Discussion	38
4.1. Self- perception and identity development in childhood	38
4.2. Others perception and identity development in childhood	39
4.3. Self- perception and identity in adulthood	40
4.4. Others perception and identity in adulthood	41
4.5. Critique of the studies reviewed	42
4.6. Implications for future reviewed and clinical implications	42
Conclusion	44
References	45

Section B: Narratives of the construction of work identity in people living with sickle cell disorder.	52
Abstract	53
1. Introduction	54
1.1. What is individual work/ occupational identity	54
1.2. Work identity development	55
1.3. Sickle cell disorder (SCD)	57
1.4. Work identity development and SCD	58
1.5. Rationale and aims	58
2. Method	59
2.1. Narrative Analysis	59
2.1.1. Quality assurance	60
2.2. Participants	61
2.3. Procedures	62
2.3.1. Interview	63
2.4. Analysis	63
2.5. Ethics	64
3. Results	64
3.1. Participants- Summary and ‘global impressions’	65
Sharon	65
Joshua	65
Christina	66
Jackie	67
Chantel	68
Charles	68
Kenneth	69
Paul	70
Pauline	71
3.2. Thematic analysis	71
3.2.1. Experiences influencing work engagement	71
The negative perception of teachers	72
Academia to work transition	73
Disclosure of Condition	74

3.2.2. Experiences influencing relationship with the organisation	75
Seeking support for work adjustment to manage health	76
Being an educator at work	77
Relationship with managers and colleagues	78
3.2.3. Experience of being unemployed	80
Coercion to leave job	80
Life on benefits	81
4. Discussion	82
4.1. Summary of findings	82
4.2. Methodological considerations	84
4.3. Clinical implications	86
4.4. Research implications	87
5. Conclusion	87
References	89

List of Tables

Number	Title	Page
Section A:		
Table 1	Erikson's stage theory in its final version	14
Table 2	Marcia (1966) four ego identity development statuses	15
Table 3	Four dimensions of Multidimensional Model of Racial Identity and their definition	17
Table 4	Peer reviewed studies	22- 24
Section B:		
Table 5	Lent et al., (1994) Social Cognitive Career Theory	56
Table 6	Participant demographics	61
Table 7	Basic phases of the narrative interview (Jovchelovitch & Bauer, 2000)	63

Section C: Supporting Information **98**

Appendix

1. Search Process	99
2. Article summary table	100
3. Study quality checklist	104
4. Authors guide for submission to British Journal of Health Psychology	106
5. Reflective Journal	111
6. Poster used for recruitment	113
7. Participant information sheet	114
8. Participant consent form and demographic questionnaire	116
9. Example transcript	118
10. Summary of study for participants	124
11. Summary of study for ethics committee	128
12. Interview Schedule	131
13. Table of storylines	132
14. Letter of full ethical approval from Salomons Ethics Panel	133

Major Research Project
Dominique Newsome BA (Hons), MSc

Section A

Identity Construction in People Living with Sickle Cell Disorder?

Word Count: 7,771 (230)

Abstract

Over 250 million people worldwide are affected by sickle cell disorder (SCD). This paper examines how people living with SCD construct their identity. Twelve peer reviewed papers that explored identity development across the life span with regards to self-perception and/or the influence of the perception of others were identified.

The research findings suggested that factors such as racial identity, pain severity, resilience, relationships with healthcare professionals, teachers and employers/colleagues and parental coping are influential to individuals living with SCD identity construction. However, research in this area was limited, particularly regarding an adult's construction of self within the work environment. Future research should endeavour to expand our understanding of identity development in individuals living with SCD into adulthood.

Key Words: Sickle cell, Identity, Stigma, Racial identity, Social perception

1. Introduction

The researcher will introduce sickle cell disorder (SCD) to produce some context of the condition and how it impacts on individuals daily functioning. To understand the construction of identity in people who have SCD, Erikson's theory will be introduced to examine the development of identity through the different life stages. Considering the social constructionist framework, our identity and sense of self is constructed through the perception of self that is reflective of our relationship with wider society (e.g. social interactions and their contexts, broader current and historical narratives) (Elliott, 2005). As a result, the paper will examine how stigmatising and discriminatory perceptions from wider society particularly towards racial identity impact on identity development.

1.1 What is Sickle Cell Disorder (SCD)?

Sickle cell disorder (SCD) is a lifelong inherited condition of haemoglobin formation. Sickle cell disorder affects over 250 million people worldwide (World Health Organization (WHO), 2006). The condition mainly affects people of African or Caribbean origin, though it is also prevalent throughout the Mediterranean, Middle East and parts of India, the Caribbean; and South and Central America (Sickle Cell Society, 2008; National Institute for Health and Care Excellence (NICE; 2012a)). SCD affects 1 in every 2,400 live births in England and is now the most common genetic condition at birth (Sickle Cell Society, 2008). The condition is inherited in an autosomal recessive pattern¹. SCD is a family of blood disorders that are expressed as sickle cell anaemia (HbSS), sickle cell thalassemia (HbSC or HbS β) or sickle haemoglobin

¹ Both copies of the gene in each cell have mutations so, the parents of the individual with SCD carry one copy of the mutated gene, but do not typically show signs and symptoms of the condition (i.e. Sickle cell trait).

C disease (HbC) (Andrews and Mooney, 1994; as cited in Jenerette, Funk & Murdaugh, 2009).

SCD is characterised by recurrent, unpredictable acute pain episodes called crises (i.e. fragile, brittle, hardened red blood cells inhibiting oxygen) (Grant, Gil, Floyd, & Abrams, 2000). Due to the physical state of the haemoglobins, their life expectancy is only 10- 20 days compared to 120 days for normal red blood cells (Barbarin & Christian, 1999). Repeated crises over an individual's lifespan may result in organ damage, having a significant impact on the individual's morbidity and mortality (NICE; 2012b). Blood transfusions provide individuals with healthy red blood cells and opiates (i.e. morphine) may be used to manage the pain. Bone marrow transplantation is suggested as the only cure but due to either a shortage of compatible donors or the inherent risk posed by the drug regimen required before transplantation it is not an option for most people (Yawn et al., 2014; Chakrabarti & Bareford, 2004).

1.2 Identity development

As there are different variations of SCD, the frequency of crises varies (Jenerette et al., 2009). As a result, an individual's experience of the condition will be based on their type of the condition and the personal relationship they develop with SCD in order to understand and cope with the challenges of the condition (Caird Camic and Thomas, 2011). Hence the illness experience is intertwined with their sense of self and identity. Identity may develop from the person's life stories, based on their self-concept, developmental stage and the contextual dimension of their life (Thomas & Schwarzbaum, 2010). Identity development is considered a dynamic, long-lasting process which involves finding the answers to the following questions: 'who am I?', 'What is my position in the community?' and 'What do I want to do in the future?'

(Erikson, 1963). At the very core of who we are as human beings is our identity (Browne, 2012). It affects how we are thought about and treated by others as our ideas of self are largely a reflection of others ideas of us (Smith, Walker, Fields, Brookins, & Seay, 1999). When an individual faces life difficulties, their personal strengths and resilience are influenced by, or the result of their personal identity (Browne, 2012). For the purposes of this review, identity will be defined as a person's distinctive sense of uniqueness as influenced by their self- perception and the perception of others (Tsang, Hui & Law, 2012). In order to understand how people living with SCD makes sense of living with the condition, it is important to understand the identity concept. So, this section will examine identity using Erikson's theory, as it considers the social influence on identity development. I will then present Marcia's model about the process of identities developing and the influence of racial identity before considering theory about the impact that others can have on identity formation, including stigma and racial identity theory.

1.2.1 Erikson's Theory

Erikson (1968) states that identity is a frame of reference individuals use to interpret their experience define their aims and directions in life. Using Erikson's model, identity is constructed by development through different stage crises (Table 1). The crises are psychosocial in nature as the psychological needs of the individual conflict with the needs of society (Erikson, 1963).

Erikson's psychosocial model highlights that as an individual achieves each crisis throughout their development, it leads to a culmination of basic virtues that support the achievement of the next crises (Cherry, 2005). In contrast, failure to achieve each

crisis may result in the individual developing a poor sense of self. Erikson emphasised the adolescent period as the crucial stage for a person to develop their identity, as this is the stage we begin to identify, examine and implement the fragile ideas of self which were encountered in childhood (Kroger, Martinussen & Marcia, 2010). Nonetheless, identity growth and development is continued after this stage. For instance, it is beneficial to develop a strong personal identity during adolescence to form better intimate relationships during early adulthood (Cherry, 2005).

Table 1. Erikson's Stage theory in its final version

Age	Conflict	Resolution or "Virtue"	Culmination in old age
Infancy (0-1 year)	Basic trust vs. Mistrust	Hope	Appreciation of interdependence and relatedness
Early childhood (1- 3 years)	Autonomy vs. Shame	Will	Acceptance of the cycle of life, from integration to disintegration
Play age (3- 6 years)	Initiative vs. Guilt	Purpose	Humour; empathy; resilience
School age (6- 12 years)	Industry vs. Inferiority	Competence	Humility; acceptance of the course of one's life and unfulfilled hopes
Adolescence (12- 19 years)	Identity vs. Confusion	Fidelity	Sense of complexity of life; merging of sensory, logical and aesthetic perception
Early adulthood (20-25 years)	Intimacy vs. Isolation	Love	Sense of the complexity of relationships; value of tenderness and loving freely
Adulthood (26-64 years)	Generativity vs. Stagnation	Care	Caring for others and agape, empathy and concern
Old age (65- death)	Integrity vs. Despair	Wisdom	Existential identity; a sense of integrity strong enough to withstand physical disintegration

1.2.2 Marcia's model

According to Marcia (1966), four possible identity statuses (Table 2) may develop as a result of:

- An individual re-examining and exploring their options and choices (i.e. has a crisis been experienced?) and
- Committing to a certain role or value (i.e. has a commitment been made?).

This model primarily focused on the adolescent stage of Erikson's psychosocial stage theory to extend the understanding of how identities develop. The four possible identity statuses are Identity Diffusion, Identity Foreclosure, Moratorium and Identity Achievement. Marcia (1967) states that individuals with achieved identity statuses are more mature and have an internal locus of self-definition.

Table 2. Marcia (1966) four ego identity development statuses

		Commitment	
		<i>Present</i>	<i>Absent</i>
Exploration	<i>Present</i>	Identity Achievement Undergone a crisis and made a commitment	Moratorium Undergone a crisis but failed to commit to a value
	<i>Absent</i>	Identity Foreclosure Not undergone a crisis but made a commitment anyway	Identity Diffusion Neither crisis nor commitment has been made

1.2.3 Racial identity

In the UK as SCD mainly affects people of African and Caribbean descent (1 in 4 West Africans and 1 in 10 Black African Caribbean; Brent Sickle Cell and Thalassaemia Centre, n.d.) and Erikson's model stresses the importance of social circumstances on identity development it is imperative to explore the development of racial identity. As it is important to acknowledge how individual perception is intertwined with when,

where and how they grew up, political, geographical, sociological and historical factors are influential on the thoughts and behaviours of that individual (Thomas & Schwarzbaum, 2010). There is 'not one singular way in which race is defined or internalised by individuals' (Royal, Jonassaint, Jonassaint & Castro 2011, p.391). Racial identity is the heterogeneity in attitudes and beliefs of a particular racial group. The variability in the significance and qualitative meaning attributed to being part of the racial group arises from the diverse cultural experiences (Royal et al., 2011). As a result, an influential determinant of identity is culture (Waldegrave, 1998; as cited in Thomas & Schwarzbaum, 2010). The existing data on race and SCD illustrates both adverse and protective effects of racial identity on health outcomes (Royal et al., 2011).

A conceptual framework to understand individual's attitudes and beliefs regarding the significance and meaning of race in their lives has been proposed by Sellers, Smith, Shelton, Rowley and Chavous (1998) in America. The model is called the Multidimensional Model of Racial Identity (MMRI) and consists of four dimensions of racial identity: salience of identity, centrality of identity, ideology associated with identity and private and public regard (Table 3). The first two dimensions acknowledge the significance of race in the individual's self- definition, whilst the second two dimensions relate to the qualitative meaning ascribed by the individual to being black.

Table 3. Four dimensions of Multidimensional Model of Racial Identity and their definition

<i>Dimensions of MMRI</i>	<i>Definition</i>
<i>Salience of identity</i>	The extent a person's race is relevant to their self- concept at a particular moment in time.
<i>Centrality of identity</i>	The extent a person normatively defines their race.
<i>Ideology associated with the identity</i>	An individual's beliefs, opinions and attitudes regarding how they feel blacks should live and interact with society.
<i>Private and public regard</i>	A person's affective and evaluative judgement of their race, through their personal opinion (private regard) and their view of others opinions (public regard).

1.2.4 Perception of others in identity development

Pierce, Kostova and Dirks (2003) evaluate the concept of psychological ownership in relation to chronic illness, and the defining of an individual's self-identity by viewing themselves through the eyes of society. Thus, the perceptions of wider society may have a consequential impact on the individual's self-identity. As the concept of ownership is also linked with the idea of control and responsibility, Karnilowicz (2011) proposed that 'improving, maintaining or protecting one's identity may result in an enhanced sense of responsibility towards the illness' (p. 227) enabling the individual to cope better. It is therefore important to consider how wider societal views may impact individual's relationship with their condition and consequentially their self-identity, particularly if the social perception is negative. In this section I will focus specifically on how stigmatising perceptions from the wider society may impact on identity development in individuals with SCD. I will first define the concept of stigma and then explore how the definition may relate to SCD.

1.2.5 Stigma

Goffman (1963) states stigma can be socially discrediting, permanent and affect the perception of the person as a whole. Three types of stigma described by Goffman (1963) may affect people living with SCD: character blemishes (e.g. substance abusers), physical deformities (e.g. yellow eyes, delayed sexual development) and tribal stigma (e.g. race). According to Miles (1981; as cited in Brunton, 1997), 'stigma was a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the person who possess them' (p.70). Link and Phelan (2001) further this description by stating that when the following interrelated components converge stigma exists:

- People distinguish and label human differences.
- Dominant cultural beliefs link labelled persons to undesirable characteristics (i.e. negative stereotypes).
- Labelled persons placed into distinct categories to accomplish some degree of separation (i.e. 'them' and 'us').
- Labelled person experiences status loss and discrimination resulting in unequal outcomes.

A little more than twenty years ago SCD could be dismissed as a condition of little interest to health and social care agencies (Atkin & Anionwu, 2010). The neglect of this condition has been attributed to the failure of the British welfare services in recognising and responding to conditions associated with minority ethnic groups (i.e. individual and institutional racism) (see Ahmad & Atkin, 1996; Streetly et al 1997 as cited in Anionwu & Atkin, 2001). Individuals with SCD often attribute the lack of interest from wider society as resulting of it being a 'black condition' (Bradby, 1996 as cited in Anionwu & Atkin, 2001). The pain crises have historically been the primary focus of

research with this population (Smith et al., 2008) and so there is limited qualitative research on the quality of life and resilience of those living with Sickle Cell Disorder, particularly in the UK. Partly as a result of this lack of evidence, ensuring ongoing development of services and the dissemination of good practise remains a struggle (Akin & Anionwu, 2010). Reviews of quantitative research in SCD consistently highlight that wider social and psychological factors influence the experience of SCD and it is difficult to understand the meaning of SCD on an individual's life without considering all aspects of the experience (Barbarin & Christian, 1999; Anie, 2005). Research has shown the stigma of having a chronic illness may affect an individual's quality and quantity of social network, ability to adapt and cope and their self-concept (Millen & Walker, 2001).

1.3 Summary and aims of the review

SCD is the most common genetic condition at birth (Sickle cell society 2008) affecting over 250 million people worldwide and rising (WHO, 2006). Research has shown that as SCD affects each person differently, particularly with regards to the frequency of crises experienced and a combination of attributes (i.e. daily burden, severity, treatment, social status) influence how an individual constructs their relationship with SCD rather than a single attribute (Caird et al., 2011; Sankar, Cho, Wolpe & Schairer, 2006). As the identity theories above demonstrate, it is the combination of both self-view and others views which coalesce to impact ones' construction of identity. This paper aims to synthesise studies examining the construction of identity in people with SCD. The findings will be discussed in relation to theoretical links and critiqued, outlining implications for clinical practise and future research. The review seeks to better understand how individuals with SCD perceive themselves as a result of the

impact of their condition and based on the perceptions of others in wider society. Through this, it is hoped that we may gain further insight into how people with SCD make sense of their experiences.

1.3.1 Key terms

Sickle cell anaemia refers to HbSS disease whereas the term sickle cell disease/ disorder refers to all of the genotypes. For the sake of this paper we will be looking at sickle cell disease/ disorder.

2. Methodology

2.1 Search procedures

An electronic search was conducted using PsycINFO, Medline and ASSIA in July 2015. For the purpose of the review, identity was defined as a person's distinctive sense of uniqueness as influenced by their self- perception (i.e. self- acceptance) and the perception of others (i.e. social perception and interpersonal perception). As a result, the following search terms were combined using boolean operators:

- *[identity] OR [self- perception] OR [self- acceptance]*

AND

- *[sickle cell] OR [sickle cell disease*] OR [sickle cell anaemia] OR [SCD].*

AND/ OR

- *[social perception] OR [interpersonal perception]*

Abstracts of the retrieved references were read, and articles were sought if the title or abstract clearly stated that the paper reported identity and sickle cell. Reference lists of all retrieved papers (i.e. both included studies and relevant conceptual papers) were

also hand- searched. From those selected papers, only those involving both identity and sickle cell disorder were included in this review.

2.2 Inclusion/exclusion criteria

As Erikson's theory highlights that identity is a developmental process through all life stages, papers were included if they explored identity development in children and adults with SCD to capture all elements of the construction in people with SCD. The searches were limited to journal papers published in English. Papers were excluded if they were unable to be attained, reviews/ articles without a study; the study was medical (i.e. examining cell identity), examined the experience of screening for SCD or following a full article review deemed inappropriate because they did not specifically address identity construction.

2.3 Search results

Refer to Appendix 1 for details of the search process. Searches were carried out on two occasions, the latest of which was conducted in October 2015. N=12 peer reviewed studies were finally included and reviewed (Table 4). See table in Appendix 2 for full details of study design, participants, measures and outcomes.

Table 4. Peer reviewed studies

Paper	Aim of paper	Study design/ Method of analyses	Type of study	Sample size; age range
Lim, Welkom, Cohen & Osunkwo (2012) <i>Evaluating the protective role of racial identity in children with sickle cell disease.</i>	This study examined whether racial identity moderates the relation between pain and quality of life in children with sickle cell disease.	Hierarchical linear regression, Chi-square, T-Test	Quantitative	100 children; 8- 18yrs
Lemanek, Horwitz & Ohene-Frempong (1994) <i>A multiperspective investigation of social competence in children with sickle cell disease.</i>	The study aimed to compare the social competence and self- perceptions of 4- to 8- year-old children with sickle cell disease to a comparison group of healthy children.	One way ANOVAs, T-Test, Pearson product moment correlations		59 children (10 females); 4yrs 1mth to 7yrs 10mths
Royal, Jonassaint, Jonassaint & Castro (2011) <i>Living with sickle cell disease: Traversing 'race' and identity.</i>	The study aimed to explore how SCD patients' race/ ancestry/ ethnicity/ nationality, their beliefs and attitudes associated with these identities relate to their SCD experiences and outcomes	ANOVA correlations		46 adults (26 females); 18- 56yrs (M=32.04yrs)
Bediako, Lavender & Yasin (2007) <i>Racial centrality and health care use among African American adult with sickle cell disease.</i>	This study examined an exploratory model of the confluence of racial centrality pain, psychological variables and health care in a sample of African American adults with sickle cell disease.	Correlational analyses		83 adults (49 females); 18- 64yrs

Bediako & Neblett (2011) <i>Optimism and perceived stress in sickle-cell disease: The role of an afrocultural social ethos.</i>	To explore whether specific variables representing an Afrocultural social ethos (i.e. spirituality, positive affect and communalism) indirectly influenced the relation between optimism and perceived stress among individuals coping with sickle cell disease.	Correlational analyses		83 adults (42 females); 18- 64yrs
Caird, Camic & Thomas (2011) <i>The lives of adults over 30 living with sickle cell disorder.</i>	To investigate the lived experience of adults over 30 years old living with sickle cell disorder and sought to develop a model understanding participants' ability to function.	Grounded theory	Qualitative	15 adults (11 females); 17- 68yrs
Campbell, Ross, Kumagai, Christner & Lypson (2010) <i>Coming of age with sickle cell disease and the role of patient as teacher.</i>	This study aimed to explore the way adolescents and young adults with sickle cell disease educate others about their condition and the meaning they give to their experiences with health care professionals.	Phenomenological Inquiry method		17 young people (9 females); 12- 28yrs
Sankar, Cho, Wolpe & Schairer (2006) <i>What is in a cause? Exploring the relationship between genetic cause and felt stigma</i>	To explore whether a genetic or hereditary basis of condition necessarily confers a stigma to the condition.	Thematic analysis; Semi-structured interviews		22 adults (13 females); 18-53yrs
Atkin & Ahmad (2001) <i>Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder.</i>	To explore the strategies and resources young people use to cope with sickle cell disorder or thalassaemia major in an attempt to take control over their lives.	Interviews		26 adolescents (14 females); 10- 19yrs (M= 14.2yrs)
Thomas & Taylor (2002) <i>The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups.</i>	To gain an understanding of the psychosocial impact of SCD and determine whether these experiences could be conceptualized in terms of quality of life as defined by the WHO with the intention of informing psychosocial research.	Phenomenological Inquiry method		17 HbSS young people and adults (10 females) 15- 35yrs

Dyson, Atkin, Culley, Dyson, Evans & Rowley (2010) <i>Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school.</i>	To identify how stigma is enacted in the context of social inequalities by exploring the experiences of young people with sickle cell disorder as they negotiate school relations in the context of chronic illness.	Mixed methodology- surveys and interviews	Mixed methods	113 young people; 4- 25yrs
Barbarin (1999) <i>Do parental coping, involvement, religiosity, and racial identity mediate children's psychological adjustment to sickle cell disease?</i>	This study compared the functioning of families with sickle cell disease to that of healthy controls matched for race and socioeconomic status.	Mixed methodology- surveys and interviews.		77 children; 5- 18yrs

2.4 Structure of Review

Each selected paper will be described in detail. Papers using a quantitative methodology will be critiqued using guidance from NICE Quality Appraisal checklist for Quantitative Intervention studies (2012), whilst papers using a qualitative methodology will be critiqued according to Yardley's (2000) 4-point model (see Appendix 3 for details for both the NICE checklist and Yardley's model). The results are then synthesized to explore identity construction in individuals with SCD firstly with regards to how they see themselves and secondly the impact of wider societal influence. Conclusions will then be drawn in terms of the research and clinical implications.

3. Main body of review

Studies focusing on the perception of self in identity construction will first be described and then critiqued by addressing the impact of SCD symptoms on identity development, the impact of the development of wider identities on SCD symptoms and the impact racial identity has on SCD symptoms. I will then address the papers that focus more prominently on the impact of others perceptions on identity construction.

3.1 Identity construction and self- perception

3.1.1 The impact of SCD on identity development

The paper by Lemanek et al. (1994) aimed to compare the social competence and self- perceptions of 59 American, 4- 8 year olds with SCD to 30 children matched without SCD from multiple perspectives (self- report, parents, teachers and clinic staff members) using one way ANOVAs, T-tests and Pearson product- moment

correlations. It was found that parent and teacher's ratings of social competence or problem behaviours were similar to those for the control group. The SCD children's social competence was reflected at an adequate level and appeared resilient to the negative effects of SCD, possibly acting as a protective factor. There was also no significant difference in self- perceived competence and acceptance in children living with SCD compared to the control group. This study provides initial evidence that having SCD does not necessarily have an impact upon self- perception, suggesting that SCD does not significantly impact on identity development in childhood.

It is important to note that the sample of SCD children were generally of good health and cognitive functional status. However, it is possible that a group with more severe symptoms of SCD may have impacted on perceived competence. The self- report of children was also not always a true representation of their ability. Observations may have supplemented the children's self-reports. The sample size of the study is sufficient to detect any deficit in findings. Further research may wish to have a longitudinal design to monitor the consistency and changes in social competence through the lifespan.

The paper by Atkin and Ahmad (2001) aimed to examine young people's identity development by examining the strategies and resources they adopt to cope with SCD in an attempt to take control over their lives using interviews. 26 British adolescents aged 10- 19 were involved in the study. It highlighted that the perceived impact of the psychosocial burden may be within and external (i.e. life transitions, changes in social relationships and racist, disablist or sexist marginalisation's) to the realms of the condition. These burdens possibly threatened and challenged the young person's

developing identity, by threatening their skills and potential. As a coping mechanism and to maintain their sense of normalcy, young people may cast others as 'victims' in an attempt to forget about SCD. They may reframe negative experiences to maintain optimism and control over their life. They also acknowledged their struggle to cope may be a natural response and used religion, particularly Christianity (mainly under 12's) to pray for relief during crises.

For some respondents a sense of reward and punishment was expressed regarding the cause of crises, illustrating a complex relationship in adapting and accepting the SCD diagnosis as part of their identity. Parents provided perceived protection from the practical problems of SCD and negative views and actions of others, delaying recognition of differences from peers; consequently, creating a strain on the parent-child relationship as it conflicted with the adolescence identity development (e.g. poor insight into parent's motives, need for independence). A positive self- perception particularly in regards to racial perception was portrayed to be an influential factor in coping with the internal and external psychosocial burdens that arise from SCD. Having medical knowledge possibly enabled young people to have a sense of control over their life. They valued the social skills and empathy of health professionals but the professional's lack of knowledge about SCD was an identified problem. This study also illustrated that individuals with a positive self- perception were considered more likely to thrive on the challenge to prove wrong the teachers who had 'written them off' because of their condition and the teacher's expectations for their racial group (i.e. Afro- Caribbean's). Racism had a perceived impact of being more debilitating than SCD when attempting to enter the workforce as it dominated their social relationships. This study locates its finding in the social context and considers the researcher's actions and characteristics in order to balance the power in the process of

investigation. The research process was disclosed and the findings provided transparency of the data. Caution is needed in generalising the results of the study as the authors stated that for some respondents their account was dependent on the status of their condition so if they had recently had a crisis their responses could be more negative than long spells without crises.

3.1.2 The impact of identity development on symptoms of SCD

The paper by Caird, et al. (2011) sought to investigate the lived experience of British adults over the age of 30 using grounded theory with an aim to develop a model of understanding individual's ability to cope. The study perceived that the depth of an individual's sense of personal identity separate from SCD enabled the individual to reject the 'sick identity' and promote a differential identity (i.e. professional) that may be considered more powerful and successful in the wider society. They achieved this by incorporating only the positive elements (e.g. self-reliance, toughness) gained through their struggle as part of their identity, developing a meaning for the condition by seeking essential knowledge of the pathophysiology of the condition and developing an awareness of their own body and how the condition affects it so they could actively start coping with the effects of SCD.

It must be noted that the findings are based on the responses of 15 participants who were attendees of a voluntary organisation had experience of group or one to one psychological support. Participants were also over the age of 30, mainly female with stable socioeconomic circumstances. Saturation of the data as a result may not have been achieved as participants are not fully representative of the wider adult SCD population. The influence of receiving peer or psychological support on acceptance

and the development/ maintenance of resilience, particularly in less stable socioeconomic conditions should be considered. Nonetheless, the research process was disclosed, and transparency of the data was provided. It was clear throughout the paper the philosophy of the approach adopted and the importance of carrying out this piece of research.

3.1.3 The impact of racial identity on symptoms of SCD and quality of life (QOL)

The paper by Lim et al. (2012) aimed to examine whether racial identity moderated the relation between pain and QOL in 100 American 8-18 year olds with SCD using hierarchical linear regression, chi-square and T- tests. The findings in children were consistent with, but not proof of a causal relationship between pain and physical, emotional, social and school function QOL dimensions, as depicted in the Paediatric Quality of Life inventory (PedsQL; Varni, Seid & Kurtin, 2001). However, the mechanisms of these relationships would warrant qualitative exploration. Findings proposed that by holding a positive personal view and feeling that others have a positive view of African American's; the child may be able to manage better in social situations. This suggests that the construction of self, particularly in regards to race is causally related to an individual's ability to function socially (i.e. QOL) and manage the pain from a young age. Lim, et al. (2012) also proposed children experiencing low pain and high regard racial identity reportedly may have a greater physical QOL than children presenting with low pain and low regard. Hence, the physical ability of a child with SCD may be affected though not conclusively by the amount of pain they experienced and by how the child viewed their own race and felt others perceived them. The paper proposed future research should consider private and public racial identity when further examining the QOL in children with SCD, as it may act as a

protective factor. Conversely, as their findings are based on correlations, causal conclusions cannot be drawn. The findings of this study are also based on a large sample size which is beneficial to identify any deficits in results. However, as the sample is a middle class American sample who attended a routine medical visits, caution must be taken when generalising to a British population, other socioeconomic backgrounds or a sample that experience acute pain crises.

The paper by Bediako et al. (2007) aimed to examine the interaction of racial centrality, pain, psychological variables and health care use in 84 American adults aged 18-64 using correlational analysis. The study proposed similar cognitively based construal and appraisal processes may underlie pain severity, perceived stress and psychological symptoms. Due to the study's cross-sectional design it is difficult to make causal inferences but the findings suggested that racial identity had a significant impact on pain severity and frequency to which adults with SCD used health care services. They proposed that less severe pain was reported and fewer health care services were used by those where being Black was central to their self-concept. Two possible suggestions were presented to explain these findings. The first is the salutogenic effects of racial identity and the second suggestion is perceived discrimination experience of stigma and being distrustful of the medical system.

In addition, racial centrality was not found to have a significant relationship with psychological variables, as measured by the Brief Symptom Inventory (Derogatis & Coons, 1993) which assessed for depressive symptoms and anxiety (Bediako et al., 2007). As the study did not examine other aspects of racial identity, further research

should directly assess the individual's positive and negative feelings about being Black and the impact this may have on pain, psychological variables and health care use.

Considering the vast age range, the size of the sample is relatively small and being based on an American sample makes generalisation of the findings difficult. In addition, the authors of the study stated that the sample was relatively healthy (no hospitalisations in month of study) and comparatively better educated than other studies.

The paper by Bediako and Neblett (2011) sought to explore whether variables representing Afro cultural social ethos (i.e. spirituality, positive affect and communalism) indirectly influenced the relation between optimism and perceived stress in individuals coping with SCD using correlational analyses. A total of 83 American adults aged 18-64 years partook in this study. The paper found the more an adult with SCD was optimistic about their condition the less stress they experienced. Further research found no significant mediation of Afro cultural social ethos variables (spirituality, positive affect and communalism) in the relationship between optimism and perceived stress. However, it was identified that positive affect and spirituality were positively related to but not proof of optimism in adults. It may be beneficial to examine further the adaptive outcomes to SCD in regards to the role of Afro cultural domains and other sociocultural factors.

Limitations of the study are participants were all attendees of outpatient's clinics, so it may not be fully representative of the wider SCD population. The sample is also relatively small for the age range explored and caution should be applied when generalising the findings.

3.2 Influence of perceptions of others on identity construction

As identity is also constructed from the perspective of others, the following papers will focus further on the impact others have on the individual with SCD identity formation through these positive and negative life experiences. The papers are presented to address the impact of school experience/ disclosure, parenting and families, stigma and others perception of their race on identity development.

3.2.1 The impact of school experience/ disclosure on identity development

The paper by Dyson et al. (2010) sought to examine how stigma is enacted in the context of social inequalities by exploring the experience of young people with SCD at school using mixed methods (e.g. surveys and interviews). 569 British children aged 4-25 years were involved in this study. The study illustrated that young people attempt to portray other aspects of their identity to ensure SCD is not perceived as the central component of who they are. Though this may result in a struggle to accept and acknowledge the reality of their SCD diagnosis. Dyson et al. (2010) study put forward that individuals are challenged in overcoming other's suspicion and ignorance regarding their condition. For some young people disclosure of the diagnosis to teachers or peers was not perceived to improve their treatment. It could have possibly brought about disabling attitudes from others and unwarranted attention which affected their ability to reject the 'sick' identity. Whereas for others, disclosing could have led to a better understanding about their bouts of illness and allowances made for their absences. This study highlights the challenge individuals face in promoting other aspects of their identity without detriment to their health. It also acknowledges that how disclosure of SCD is received and responded to by others may influence the individual's ability to construct their preferred identity.

Limitations are due to the large sample; all children did not complete all aspects of the study. The data and clinical severity of their condition was also self-reported rather than medical records which may lead to social desirability bias.

The paper by Campbell et al. (2010) sought to explore the way adolescents and young adults with SCD educate others about their condition and the meaning they attributed to their experiences using a phenomenological inquiry method on interviews. The sample consisted of 17 American young people age ranging from 12 to 28 years. Young adults with SCD recognised the high prevalence of their condition amongst African American population in contrast to the limited knowledge of the condition amongst their family, peers, teachers and medical staff. The study illustrated that teachers may believe the pain is an excuse for the young person to avoid mandatory activities. This may enforce the development of an identity that they were not academically motivated or capable. This study further proposed that the ignorance and negative regard from others in society often led to a common misperception of SCD patients as drug abusers resulting in significant consequences (i.e. medical errors) for the person with SCD. These negative perceptions from others in wider society if internalised could have a detrimental impact on the individual's identity construction as they conflict with their strength of character and belief system that they are capable of coping. A coping strategy highlighted in this study was the identity development of the patient as the teacher. Though this is a positive identity reconstruction for the individual, when chronically ill it becomes increasingly difficult for them to act as an advocate for themselves and continually survey over their own care. This identification also introduces a change in power dynamics between the patient and the provider. Frustration may arise when critical information is withheld

from the individual about their daily care, particularly when the lack of knowledge about their condition has been identified.

This paper explains the philosophy of the approach adopted but does not consider the impact of the researcher's actions or characteristics. Saturation of the data was achieved and transparency of the data was provided through excerpts. Nonetheless, caution must be taken in generalising the findings, particularly to a British population.

3.2.2 The impact of parenting and families on positive identity development

The paper by Barbarin (1999) aimed to compare the functioning of 77 families affected by SCD to 74 healthy control families matched for race and socioeconomic status in America, using mixed methods analysis (e.g. surveys and interviews). The children in the study ranged from 5-18 years old.

The study suggests the emotional wellbeing of parents, religiosity and emotional support that enhanced parental coping were consistent with but not proof of moderating the adverse effects of SCD for children. These factors were considered protective against the negative comparisons to peers as they enabled positive, compassionate, resilient and secure identities to be constructed despite the individual's challenges. The areas of their lives most commonly reported by children and adolescents as affected by SCD were the activities they were able to participate in, issues related possibly to stigma from wider society and infantilisation from family and friends to protect them from discrimination. Individuals living with SCD were also reported to adopt identities that provided a positive meaning regarding the cause and controllability or religious interpretation of the condition in order to cope with the recurrent crises.

Caution should be taken when comparing the findings to a British sample as this is based on an American population. The study was also sampled through nominations from the SCD family and advertisements in neighbourhoods and schools stating a \$70 incentive. This may have led to control families which were motivated by the incentive and findings skewed by social desirability bias.

3.2.3 The impact of stigma on identity development

The paper by Thomas and Taylor (2002) aimed to examine the psychosocial impact of SCD and determine whether these experiences could be conceptualized in terms of quality of life as defined by the WHO using a phenomenological inquiry method with patient- led focus groups. 17 British people aged 15- 35 living with HbSS were involved in the study. Six themes were identified and illustrated that how an individual constructs their identity is affected by the huge psychosocial burden affecting an individual's QOL (i.e. physical, psychological, social and occupational wellbeing) as these factors influence how they see themselves and how others perceive them.

The theme 'growing up with SCD' identified that due to parental guilt for the genetic component of SCD, parents may be perceived as in denial or overprotective/ restrictive of the child's activities resulting in the sick identity being perceived as shameful or limiting. This theme also addressed how stigma (Goffman, 1963) towards the physical deformities (i.e. yellow eyes) of the condition could possibly reduce their ability to live normally (see Erskine, 2012). Inadvertently, these experiences affected how a child saw themselves (e.g. 'I have a shortened life span') and related to others (e.g. reluctant to make friends). The 'education' theme emphasised the perceived impact of the teacher's lack of understanding of the condition but despite the negative perceptions

individual's performed at their best, pertaining to their resilience to strengthen positive identities. This paper describes in the 'unremitting nature of the SCD' how the persistent fight with the condition caused either depressive states or instilled a drive to live normally and take risks. Concerns were identified in the 'employment' theme about disclosure, proving sickness, losing their job or lack of promotions as a result of the condition and the negative attitudes of employers. It addressed how strengthened positive identities were possibly developed despite social and financial risks (see All Party Parliamentary Group (APPG), 2009). The 'relationships' theme stated the bidirectional impact of the condition on partners and relatives and their difficulties in coping. How an individual perceived themselves possibly provided the coping mechanisms that had a vital impact on their relationships. Negative self-perceptions could have a negative impact on intimacy and trust likely leading to strained relationships and isolation. The 'hospitalisation' theme detailed how stigma (Goffman, 1963) due to character blemishes (i.e. drug seeking) could create distress and anger. Rather than strengthening identities that consider the individual knowledgeable due to their past experiences (Jacob, 2001) individuals are quite likely to be ignored, not believed or stereotyped (see Maxwell & Streetly, 1988; Smith et al., 2005).

The findings illustrated the different aspects of an individual with SCD, quality of life that may be affected by the condition and the impact on the formation of positive and negative identities, linking back to current empirical evidence. The findings were transparent and the research process was disclosed. The study explained the impact and importance of this study.

The paper by Sankar et al. (2006) aimed to explore the relationship between the cause of the individual's conditions and the experienced stigma using thematic analysis on semi- structured interviews. The study examined four different conditions; the SCD condition consisted of 22 American adults ranging from 18- 53 years old.

Acquaintances may perceive the family as flawed due to the presence of the condition. As a result, individuals may be ostracised and this negative perception may be internalised. Providing knowledge of the condition's genetic nature created relief for family and friends (i.e. not contagious) and exposed the importance and need for families to consider genetic testing. The genetic cause was also likely to connect the individual to an African ancestry which for some individuals strengthened their positive identity by grounding their history and providing them with a sense of belonging.

A limitation of the findings of this study is that participants were volunteers, which suggests they were more accepting of their condition and therefore some resilience/ tolerance to the stigma experienced from wider society regarding their condition. Generalisation of the findings to a British population may be difficult because of the American sample. Nevertheless, the paper explains the social context of the research and the findings impact and importance. Transparency of the data is provided but it is difficult to deduce whether saturation of the data was achieved.

3.2.4 The impact of others perceptions of race on SCD identity

The paper by Royal et al. (2011) aimed to explore the relationship between the personal beliefs and attitudes associated with the individual's affected by SCD's race/ ancestry/ ethnicity/nationality identities and their SCD experiences and outcomes

using ANOVA correlations. The sample consisted of 46 American adults with ages ranging between 18 and 59 years.

In contrast to Bediako et al. (2007) this paper states no significant correlations were identified between racial identity, the severity of SCD and frequency of hospitalisations. However, it suggested that individuals who believed their condition was influential in how others perceived and treated them were quite likely to feel the wider society had a low regard for their race. It was proposed individuals may focus on similarities between their race and the wider mainstream society to reduce the tension that could also arise between the individual's personal positive attitudes and the general negative societal attitudes towards Black people. The study stated this tension could result in stress which had a significant impact on their condition. Royal et al. (2011) proposed, if people with SCD defined themselves according to race and stressed the uniqueness of their race they were more likely inclined to believe that their race influenced their experience with SCD.

The authors acknowledged that the nationality of the participants were not reliably collected, and in respect of that the findings based on the MMRI should be considered with caution as it is not validated on a non-black population. The sample size for this study is also extremely small for the relative age range of participants and the American sample makes it difficult to generalise the scores to a British population.

4. Discussion

4.1 Self- perception and identity development in childhood

Studies critiqued above propose that differences between children with SCD and their peers are subtle and less apparent suggesting a similar experience of identity

development until they reach adolescence (Lemanek et al., 1994). Perceiving others to have a positive view of their race (Lim et al., 2012) and parents reducing the experienced stigma (Barbarin, 1999; Atkin & Ahmad, 2001) possibly enabled the child up until this stage to 'live normally'. During adolescence, physical, psychological and emotional differences from their peers may become more significantly apparent and due to possible ruptures in parental relationships there may be increased recognition of other's perception (Atkin & Ahmad, 2001). Hormonal changes were consistent with but not proof of, a causal relationship to frequent crises, affecting the adolescent's ability to explore different identities, to live normally and possibly heighten the differences from their peers (Dyson et al., 2010). Erikson's theory identifies this stage as the formation of an individual's identity. It was proposed that adolescents living with SCD develop a range of strategies to cope but if unable to manage these difficulties they may subsequently struggle to achieve an identity that is fulfilling (Campbell et al., 2010; Dyson et al., 2010).

4.2 Other's perception and identity development in childhood

The perceptions of others in schools possibly led to differing impacts on the young person's ability to reject their sick identity (Atkin & Ahmad, 2001; Thomas & Taylor, 2002; Campbell et al., 2010; Dyson et al., 2010). Lack of support was perceived to increase stigma and discrimination (e.g. disabling attitudes) which if internalised could possibly affect their confidence in completing academic work and attitude towards the working world (e.g. not smart enough to do certain jobs). Whereas, increased support had a perceived impact in reducing shame/ guilt for absences and extended their support system to the school environment (Thomas & Taylor, 2002; Campbell et al.,

2010; Dyson et al., 2010). This is important to consider in implementing clinical support.

The quality of their parents' ability to cope with their condition and positive support by others was consistent with but not proof of a causal relationship to positive, compassionate, resilient and secure identity development despite challenges experienced (Barbarin, 1999). The support had a perceived impact in reinforcing other positive aspects of identity, rejecting the 'sick identity', promoting exploration and permitting commitment to encourage identity achievement so they could 'live normally' (Dyson et al., 2010; Lim et al., 2012). Consequently, negative perceptions from family and friends were consistent with but not proof of detrimental identity development as they were ostracised (Thomas & Taylor, 2002; Sankar et al., 2006).

4.3 Self- perception and identity in adulthood

Reviewing identity development research into adulthood enables an understanding of how developing a stable identity in adolescence may affect later self- perception. The research indicated that as an adult with SCD gets older their condition continues to worsen, leading possibly to negative consequences on the individual's emotional and psychological wellbeing (Caird et al., 2011). Personal (e.g. high racial centrality, optimism) and structural (e.g. support network) factors may have a perceived impact in the individual's management of the condition (Bediako et al., 2007; Bediako & Neblett, 2011). Research found that as SCD is more encapsulated in the individual's identity, their ability to manage SCD may be perceived to improve over time and they may become more appreciative of their life (Thomas & Taylor, 2002; Caird et al., 2011; Dyson et al., 2010). Through understanding the genetic cause of their condition,

shame of SCD was perceived to reduce and their identity possibly strengthened through knowledge of an African ancestry as it was considered to provide a sense of belonging and defined who they are (Sankar et al., 2006).

4.4 Other's perception and identity in adulthood

Individuals were portrayed to be challenged in overcoming the suspicions and ignorance of others towards their condition in a number of settings and were suggested to focus on their similarities with the wider society to reduce the tension (Dyson et al., 2010). Research proposed the more individuals identified with their race the more they believed their race to influence their SCD experience (Royal et al., 2011; Lim et al., 2012). As these findings are based on correlational data, qualitative exploration may provide a more substantial justification for these findings.

Individuals living with SCD were perceived to be challenged with the suspicion from health care professionals of being drug abusers (Thomas & Taylor, 2002; Campbell et al., 2010). Depending on whether the individual with SCD positioned healthcare services as the experts or held a strong, positive identity, had a possible impact on whether they internalised these negative perceptions or avoided/ rejected the services and sought alternative methods of care (Bediako et al., 2007). Identification as a teacher was proposed as a coping strategy adopted to combat the negative perceptions and stigma of health care services (Campbell et al., 2010; Caird et al., 2011). However, as the person becomes unwell it is possible this may be increasingly difficult and lead to increased dependency on caregivers into adulthood or periods of dependency on their partners if they are in a relationship (Thomas & Taylor, 2002). It is considered likely to reinforce restrictive and hopeless identities as the individual may

be unable to progress through Erikson's stages of identity development without periods of regression, which may cause feelings of shame and depression.

4.5 Critique of the studies reviewed

As most of the research is based on small American samples and correlational data caution must be taken in generalising these findings, particularly regarding racial identity to the wider sickle cell community and making inferences. Due to the cultural differences (i.e. conscious discussions of slavery) between the UK and USA, research on SCD in the USA is often based on the individual's race. Despite the invariable connection between SCD and race, race and racism has generally been marginalised in UK sickle cell research and so little is known about how these constructs shape the sickle cell experience. Samples for these studies may also be biased as they are mainly volunteers who possibly have acceptance of their condition, resilience to the stigma in wider society and/ or responding to the offered incentive to take part (i.e. social desirability bias).

4.6 Implications for future research and clinical implications

Further research may wish to unpick in more detail the other forms and impact of stigma encountered by the wider SCD society, as racial identity is not a concept considered in the research literature for a British population. Research may also wish to further examine whether racial identity is related to the severity of SCD and hospitalisations as this review found no clear evidence. Racial identity may be important to consider when working with individual's living with SCD as the research shows that it can affect their relationship with the condition.

It may be beneficial to examine further the mechanisms of how pain may affect a child with sickle cell disorder's QOL (i.e. physical, emotional, social and school function). This may inform how to prevent damage to adolescent psychological wellbeing and identity development and could inform the development of resilience to unpredictable crises from a young age thus, enabling the child to 'live normally' and support against challenges to autonomy and identity development in adolescence.

Evidence stated the negative perceptions of healthcare professionals within this review but further research may wish to explore how the challenges that arise from these negative perceptions impact an individual affected by SCD's identity. The review highlighted that it may be beneficial to have further examination of the challenges that may arise if the caregiver or partner is not as knowledgeable about SCD and relies on the expertise of the healthcare service. It is suspected that it may also be challenging if the relationship between the individual with SCD and the caregiver or partner is strained, so exploring these experiences may be beneficial to understanding how people living with SCD cope and the constructed identities enforced when their social support network is jeopardised.

Stable identity development in adolescence according to Erikson's theory would explain how an adult living with SCD achieves generativity or stagnation. Research may explore whether generativity or stagnation is achieved as a result of their experience of work or the influence of employer's and colleague's perceptions. Further research may wish to explore if the perceptions of others in the workplace has an impact on how the individuals view themselves and the identities constructed through these interactions. This would provide information in a similar fashion to how research has explored the impact of social interactions of children with SCD at school. The findings suggest it is important in clinical work to educate teachers and peers

about SCD and increase the amount of support children receive in the school environment. Currently it can be deduced based on these findings that disclosing SCD in the school setting must be decided on individual case basis.

Conclusion

This review provides a tentative introduction to the identity development of individuals living with SCD by regarding how they see themselves and secondly the impact of wider societal influence. Many factors (i.e. resilience, racial identity, pain severity, disclosure at school/work, parental coping, relationship with healthcare professionals) seem to influence this complex process resulting in the multitude of individual experiences of coping with this unpredictable, unseen chronic illness. However, limited research in this area and the inherent design limitations make this area of research challenging. Further research has been suggested to expand our understanding of how an individual living with SCD constructs their identity.

References

- All Party Parliamentary Group. (2009). *The Social Aspects of Sickle Cell Disease and Thalassaemia in Children and Young people*. Retrieved from <http://www.dmu.ac.uk/documents/health-and-life-sciences-documents/sickle-cell/appgreportmarch2009.pdf>
- Ahmad, W. I. U., & Atkin, K. (1996). Ethnicity and caring for a disabled child: The case of children with sickle cell or thalassaemia. *The British Journal of Social work*, 26, 755- 775. DOI: 10.1177/136345939800200303
- Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology*, 129, 723- 729. DOI: 10.1111/j.1365-2141.2005.05500.x
- Anionwu. E. N., & Atkin, K. (2001). *The politics of sickle cell and thalassaemia*. Buckingham: Open university Press.
- Atkin, K., & Ahmad, W. I. U. (2001). Living a 'normal' life: Young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 53, 615- 626. DOI: 10.1016/S0277-9536(00)00364-6
- Atkin, K., & Anionwu, E. N. (2010). The social consequences of sickle cell and thalassaemia: Improving the quality of support. *Better Health Briefing*, 17. Retrieved from <http://www.better-health.org.uk/sites/default/files/briefings/downloads/health-brief17.pdf>
- Barbarin, O. A. (1999). Do parental coping, involvement, religiosity, and racial identity mediate children's psychological adjustment to sickle cell disease. *Journal of Black Psychology*, 25, 391- 426. DOI: 10.1177/0095798499025003008
- Barbarin, O. A., & Christian, M. (1999). The social and cultural context of coping with sickle cell disease: A review of biomedical and psychosocial issues. *Journal of Black Psychology*, 25, 277- 293. DOI: 10.1177/0095798499025003002

- Bediako, S. M., Lavender, A. R., & Yasin, Z. (2007). Racial centrality and health care use among African American adults with sickle cell disease. *Journal of Black Psychology*, 33, 422- 438. DOI: 10.1177/0095798407307044
- Bediako, S. M., & Neblett, E. W. (2011). Optimism and perceived stress in sickle cell disease: The role of an Afrocultural social ethos. *Journal of Black Psychology*, 37, 234- 253. DOI: 10.1177/0095798410385681
- Brent Sickle Cell and Thalassaemia Centre. (n.d.). *Sickle Cell for Healthcare Professionals*. Retrieved from <http://www.sickle-thal.nwh.nhs.uk/forhealthcareprofessionals/sicklecellforhealthcareprofessionals.aspx>
- Browne II, J. R. (2012). *Walking the equity talk: A guide for culturally courageous leadership in school communities*. California: Corwin Press
- Brunton, K. (1997). Stigma. *Journal of Advanced Nursing*, 26, 891- 898. DOI: 10.1046/j.1365-2648.1997.00442.x
- Caird, H., Camic, P. M., & Thomas, V. (2011). The lives of adults over 30 living with sickle cell disorder. *British Journal of Health Psychology*, 16, 542- 558. DOI: 10.1348/135910710X529278
- Campbell, A. D., Ross, P. T., Kumagai, A. K., Christner, J. G., & Lypson, M. L. (2010). Coming of age with sickle cell disease and the role of patient as teacher. *Journal of the National Medical Association*, 102, 1073- 1078. DOI: 10.1016/S0027-9684(15)30735-5
- Chakrabarti, S., & Bareford, D. (2004). Will developments in allogenic transplantation influence treatment of adult patients with sickle cell disease? *Biology of Blood and Marrow Transplantation*, 10, 23- 31. DOI: 10.1016/j.bbmt.2003.09.004

- Cherry, K. A. (2005). Erikson's stages of psychosocial development. Retrieved from <http://psychology.about.com/od/psychosocialtheories/a/psychosocial.htm>
- Derogatis, L. R., & Coons, H. L. (1993). Self- report measures of stress. In L. R. Goldberger & S. Bereznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects* (2nd ed., pp. 200-233). New York: Free Press
- Dyson, M. S., Atkin, K., Culley, L. A., Dyson, S. E., Evans, H., & Rowley, D. T. (2000). Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school. *Social Science & Medicine*, 70, 2036- 2044. DOI: 10.1016/j.socscimed.2010.03.010
- Elliott, J. (2005). *Using narrative in social research*. London: Sage Publications
- Erikson, E. H. (1963). *Childhood and society* (Rev. ed.). New York: Norton.
- Erikson, E. (1968). *Identity, youth and crisis*. New York: Norton.
- Erskine, R. (2012). Adolescent boy with sickle cell disease: A qualitative study. *Clinical Child Psychology and Psychiatry*, 17, 17-31. DOI: 10.1177/1359104511399843
- Goffman, E. (1963). *Notes on the management of spoiled identity*. Englewood Cliffs, NJ.: Prentice Hall
- Grant, M. M., Gil, K. M., Floyd, M. Y., & Abrams, M. (2000). Depression and functioning in relation to health care use in sickle cell disease. *Annals of Behavioral Medicine*, 22, 149- 157. DOI: 10.1007/BF02895779
- Jacob, E. (2001). Pain management in sickle cell disease. *Pain Management Nursing*, 2, 121- 131. DOI: 10.1053/jpmn.2001.26297
- Jenerette, C., Funk, M., & Murdaugh, C. (2009). Sickle cell disease: A stigmatizing condition that may lead to depression. *Issues in Mental Health Nursing*, 26, 1081- 1101. DOI: 10.1080/01612840500280745

- Karnilowicz, W. (2011). Identity and psychological ownership in chronic illness and disease state. *European Journal of Cancer care*, 20, 276- 282. DOI: 10.1111/j.1365-2354.2010.01220.x
- Kroger, J., Martinussen, M., & Marcia, J. E. (2010). Identity status change during adolescence and young adulthood: A meta- analysis. *Journal of Adolescence*, 33, 683- 698. DOI: 10.1016/j.adolescence.2009.11.002
- Lemanek, K. L., Horwitz, W., & Ohene- Frempong, K. (1994). A multiperspective investigation of social competence in children with sickle cell disease. *Journal of Pediatric Psychology*, 19, 443- 456. DOI: 10.1093/jpepsy/19.4.443
- Lim, C. S., Welkom, J. S., Cohen, L. L., & Osunkwo, I. (2012). Evaluating the protective role of racial identity in children with sickle cell disease. *Journal of Pediatric Psychology*, 37, 832- 842. DOI: 10.1093/jpepsy/jss059
- Link, B. G., & Phelan, J. C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 365- 385. DOI: 10.1146/annurev.soc.27.1.363
- Marcia, J. E. (1966). Development and validation of ego-identity status. *Journal of Personality and Social Psychology*, 3, 551- 558. DOI: 10.1037/h0023281
- Marcia, J. (1967). Ego identity status: Relationship to change in self- esteem, “general maladjustment” and authoritarianism. *Journal of Personality*, 35, 119- 133. DOI: 10.1111/j.1467-6494.1967.tb01419.x
- Maxwell, K., & Streetly, A. (1998). Living with sickle cell pain. *Nursing standard*, 13 (9), 33.
- Millen, N., & Walker, C. (2001). Overcoming the stigma of chronic illness: Strategies for normalisation of a ‘spoiled identity’. *Health Sociology Review*, 10 (2), 89- 97. DOI: 10.5172/hesr.2001.10.2.89

National Institute for Health and Care Excellence. (2012). *Sickle Cell acute painful episode: Management of an acute painful sickle cell episode in hospital.*

Retrieved from <http://www.nice.org.uk/nicemedia/live/13772/59765/59765.pdf>

National Institute for Health and Care Excellence. (2012). *Methods for the development of NICE public health guidance (third edition) Appendix G.*

Retrieved from <https://www.nice.org.uk/article/pmg4/chapter/appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and-associations>

Pierce, J. L., Kostova, T., & Dirks, K. T. (2003). The state of psychological ownership: Integrating and extending a century of research. *Review of general psychology*, 7, 84- 107. DOI: 10.1037/1089-2680.7.1.84

Royal, C. D., Jonassaint, C. R., Jonassaint, J. C., & De Castro, L. M. (2011). Living with sickle cell disease: transversing 'race' and identity. *Ethnicity & Health*, 16, 389- 404. DOI: 10.1080/13557858.2011.563283

Sankar, P., Cho, M. K., Wolpe, P. R., & Schairer, C. (2006). What is in a genetic cause? Exploring the relationship between genetic cause and felt stigma. *Genetic in Medicine*, 8, 33- 42. DOI: 10.1097/01.gim.0000195894.67756.8b

Sellers, R. M., Smith, M. A., Shelton, J. N., Rowley, S. A. J., & Chavous, T. M. (1998). Multidimensional model of racial identity: A reconceptualization of African American racial identity. *Personality and Social Psychology Review*, 2, 18- 39. DOI: 10.1207/s15327957pspr0201_2

Sickle Cell Society. (2008). *Standards for the clinical care of adults with sickle cell disease in the UK. London: Sickle cell society.* Retrieved from <https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCEQFjAA&url=http%3A%2F%2Fsct.screening.nhs.uk%2F>

[2Fgetdata.php%3Fid%3D10991&ei=6UCVVdXmBsTZ-
QHezavIBw&usg=AFQjCNGxIAgykNfzG2kxxug7RXHioNP3cA](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10991150/)

- Smith, W. R., Bovberg, V. E., Penberthy, L. T., McClish, D. K., Levenson, J. L., Roberts, J. D., ... Aisiku, I. P. (2005). Understanding pain and improving management of sickle cell disease: The PiSCES study. *Journal of the National Medical Association*, 97, 183- 193. DOI: 10.1097/PSY.0b013e31815ff5c5
- Smith, W. R., Penberthy, L. T., Bovbjerg, V. E., McClish, D. K., Roberts, J. D., Dahman, B., ... Roseff, S. D. (2008). Daily assessment of pain in adults with sickle cell disease. *Annals of Internal Medicine*, 148, 94- 101. DOI: 10.7326/0003-4819-148-2-200801150-00004
- Smith, E. P., Walker, K., Fields, L., Brookins, C.C., & Seay, R. C. (1999). Ethnic identity and its relationship to self- esteem, perceived efficacy and prosocial attitudes in early adolescence. *Journal of Adolescence*, 22, 867- 880. DOI: 10.1006/jado.1999.0281
- Thomas, A. J., & Schwarzbaum, S. E. (2010). *Culture and Identity: Life stories for counsellors and therapists*. London: Sage Publications
- Thomas, V. J. & Taylor, L. M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. *British Journal of Health Psychology* 7, 345- 363. DOI: 10.1348/135910702760213724
- Tsang, S. K. M., Hui, E. K. P. & Law, B. C. M. (2012). Positive identity as a positive youth development construct: A conceptual review. *The Scientific World Journal*, 529691. DOI: 10.1100/2012/529691
- Varni, J. W., Seid, M., & Kurtin, P. (2001). PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and

patient populations. *Medical Care*, 39, 800-812. DOI: 10.1097/00005650-200108000-00006

World Health Organization. (2006). *Sickle- cell anaemia: Report by the secretariat*.

Retrieved from http://apps.who.int/gb/archive/pdf_files/WHA59/A59_9-en.pdf

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215- 228. DOI: 10.1080/08870440008400302

Yawn, B. P., Buchanan, G. R., Afenyi-Annan, A. N., Ballas, S. K., Hassell, K. L., James, A. H.,...John- Sowah, J. (2014). Management of sickle cell disease: summary of the 2014 evidence based report by expert panel members. *JAMA*, 312, 1033- 1048. DOI: 10.1001/jama.2014.10517

Major Research Project
Dominique Newsome BA (Hons), MSc

Section B

Narratives of the Construction of Work Identity in People Living with Sickle Cell Disorder

For submission to the British Journal of Health Psychology¹

Word Count: 8,000 (346)

All names and other identifying features have been anonymised to protect
participants' identity

¹ Where possible authors' guidelines have been followed (Appendix 4)

Abstract

Background

This study explored the narratives people living with sickle cell disorder construct to explain how the experience of employment influences their identity and subsequently their quality of life.

Method

Nine individuals with sickle cell disorder were interviewed and gave detailed autobiographical narratives which were transcribed and processed using narratives analysis. Participants were 4 men and 5 women aged between 22 and 60 years.

Results

Participants' passion for their job roles was illustrated by their positive work identities. Earlier experiences were felt to be influential on drive and resilience to work challenges. In the narratives, poor understanding of sickle cell disorder by organisations and reduced ability to manage their condition impacted physical health, psychological and emotional wellbeing, social and cultural experiences.

Conclusions

This study has implications for the clinical practice and future research of adults living with sickle cell disorder, contributing to the broadening general understanding of sickle cell disorder.

1. Introduction

1.1. What is individual work/ occupational identity?

Individuals spend a large proportion of their lives at work or thinking about work when they are not there (Feldman, 1988). Arguably the primary factor determining the quality of an individual's life is work as it is central to their life; entrenched in their social and psychological identity (Beatty & Joffe, 2006). Walsh and Gordon (2008) state that when individuals perform their jobs and enact their careers their work identity is reflected as the 'claimed central character' that is then reflected in the specific job-related roles influencing the individual's work- behaviours. Work or occupational identity is an emerging concept (Phelan & Kinsella, 2009). Kielhofner's (2009) definition is focused on the individual's development and states it as 'a composite sense of whom one is and wishes to become as an occupational being generated from ones' history of occupational participation' (p.170). Various researchers (Adler & Adler, 1988; Kramer & Brewer, 1984; Mael & Ashforth, 1992, 1995; O' Reilly & Chatman, 1986; Skorikov & Vondracek, 2011) have linked a strongly developed positive work identity to commitment, loyalty, cooperation and supportive behaviours at work giving meaning and direction to one's career.

Work identity construction is an ongoing process (Rudman & Dennhardt, 2008). The psychosocial stage, generativity vs. stagnation (Erikson, 1956) highlighted that perceived failure at work in adulthood may lead to feelings of being unproductive and uninvolved in the world. Hence, a work identity that is 'worthy and correct, yields a sense of accomplishment, provides grounding in familiar routines and allows one to realise one's unique potentials, limitations and desires' (Kielhofner, 2002; p. 150). As identity develops from collected life stories it is possible to recognise that professional and personal life changes are influenced and reinforced by each other constantly

(Erikson, 1968; Gould, 1978). Researchers (Unruh, 2004; Christiansen, 1999) highlight that as we are defined socially by what we do and our interpretations of those actions in the context of our relationships with others, though there are distinctions between our public and private identities they recurrently overlap through the lifespan. Hence, it is important to also consider people's family narratives, structure and expectations as this provides insight into their occupational motivations (Feldman, 1988).

1.2. Work identity development

As an individual's strengths and weaknesses become apparent to them from childhood these qualities in adulthood can be tailored to suit their aspired career (Holland & Nichols, 1964; Latack, 1981). Social Cognitive Career Theory (SCCT; Lent, Brown & Hackett, 1994) states that career interests are regulated by three primary tenets: self-efficacy, outcome expectations and goals (Table 5). A balanced and unified work identity is sought through exploration of a variety of occupations (Unruh, 2004; Unruh, Versnel & Kerr, 2002). Empirical evidence indicates that career aspirations can be affected by parental influence (Blau, Gustad, Jessor, Parnes & Wilcock, 1956) as parents are a source of information about career options.

Table 5. Lent et al. (1994) Social Cognitive Career Theory

Three primary tenets	Features of this tenet
<i>Self- efficacy</i>	The beliefs people have about their ability to successfully complete the steps required for a given task. Individuals develop their sense of self- efficacy from personal performance, learning by example, social interactions and how they feel in a situation
<i>Outcome expectations</i>	The beliefs related to the consequences of performing a specific behaviour. Typically, outcome expectations are formed through past experiences, either direct or vicarious and the perceived results of these experiences.
<i>Goals</i>	The decisions to begin a particular activity or future plan. Behaviour is organised or sustained based on these set goals.

A person's work identity may be considered a combination of: habits and routines; sense of mastery; interests; roles; values and perceptions of the environment (Navar & Stanley, 2015). Work identity may shift and change fluidly according to how these features align with membership to a career and may enhance their self- concept, as individuals seek identities which highlight their distinctiveness and enable status enhancement (Walsh & Gordon, 2008). Individuals will refer back to the missed opportunities, accidents avoided, obstacles overcome or wrong decisions that jeopardised 'real' possibilities, as fantasies are vital in the development of work identity (Obodaru, 2012).

Empirical studies suggest that an unstable economic employment status affects work identity as it calls for frequent reinventions of self and adjustment to identifying to an organisation for indeterminate periods of time (Fineman, 1979; Jahoda, 1982; Warr & Jackson, 1984; Gabriel, 2005; Fraher & Gabriel, 2014). The psychological effects of job loss are characterised by isolation, withdrawal and stigmatisation (Letkemann, 2002). Many may develop new narratives to reconstruct the job loss and create positive future trajectories (Parry, 2003) though the experience of unemployment

continues to have an active role, even if it does not define their identity (Fraher & Gabriel, 2014).

1.3. Sickle cell disorder (SCD)

SCD is a lifelong inherited condition of haemoglobin formation that affects over 250 million people worldwide (World Health Organization (WHO), 2006). SCD is a family of blood disorders inherited in an autosomal recessive pattern (Andrews and Mooney, 1994; as cited in Jenerette, Funk & Murdaugh, 2009). SCD is characterised by recurrent, unpredictable acute pain episodes called crises (i.e. fragile, brittle, hardened red blood cells inhibiting oxygen) (Grant, Gil, Floyd, & Abrams, 2000) which subsequently may result in organ damage and impact an individual's morbidity and mortality (National Institute for Health and Care Excellence (NICE), 2012a). It affects 1 in every 2,400 live births in England and is now the most common genetic condition at birth (Sickle Cell Society, 2008). The condition mainly affects people of African or Caribbean origin, though it is also prevalent throughout the Mediterranean, Middle East and parts of India, the Caribbean; and South and Central America (Sickle Cell Society, 2008; NICE, 2012b).

1.4. Work identity development and SCD

There has been very little empirical research implemented to explore the work identity of individuals living with SCD. Empirical evidence has focused more specifically on the impact of other chronic illnesses (i.e. HIV) and, as stated by Walker (2010), the impact after a career has been established. Living with SCD, a lifelong inherited condition of haemoglobin formation characterised by recurrent crises, an individual

may accept early on the restrictions to their work life due to the unpredictability of SCD crises, poor education and poor physical health (Bediako, 2010). To create a realisable vision of their future they may reformulate their work identity (Rudman & Dennhardt, 2008; Braveman & Helfrich, 2001).

Unemployment is prevalent among people with SCD; there are no UK figures available but USA- based estimates are 40-60% (Abrams, Phillips & Whitworth, 1994; Bediako, Lavender & Yasin, 2007; Gil, Carson, Porter, Scipio, Bediako & Orringer, 2004; Bediako, 2010). The UK Sickle Cell society (2008) stated greater employment support and training opportunities would help; as people with SCD find it difficult to gain fulfilling and financially rewarding employment, due to lack of support, employers' ignorance, inflexibility and inability to accommodate difference (All Party Parliamentary Group (APPG), 2009).

1.5. Rationale and Aims

Focusing on SCD specifically may contribute to our understanding of how life-long disability may limit or permit different occupational choices for the individual. Currently there is limited research on how individuals living with SCD may achieve generativity (Erikson, 1968) through their occupational experience. Exploration of the personal life stories of individuals living with SCD would provide a context for their occupational motivations; develop an understanding of how they construct their work identities and could have implications for organisations' human resource initiatives. Consequently, the aims were to explore the narratives people living with SCD constructed to explain how the experience of employment impacted their identity and retrospectively their quality of life by examining the following research questions:

- a. How does a sample of people with SCD understand and construct their work identity?
- b. What are the core narratives used to describe the impact employment has on psychological wellbeing?
- c. What are the core narratives those with SCD use to describe the impact employment has on physical health?
- d. Are there common narratives participants use to describe their social and cultural experience of employment?

2. Method

2.1. Narrative Analysis

In an attempt to understand the experiences of living with SCD and developing a work identity, the researcher adopted a narrative approach (Bamberg, 2004, 2011; Reissman, 1993; Wells, 2011). Current quantitative research in SCD highlights that wider social and psychological factors influence experience and so it can be difficult to understand the meaning of SCD on an individuals' life without considering all aspects of the experience (Barbarin & Christian, 1999; Anie, 2005). Narrative analysis is an umbrella term for methods that interpret storied language (Reissman, 2008). A sense of the world is gained through drawing upon established narratives; narratives are not 'the truth' about the world but rather the ability to gain a sense of 'what is true' as created by the person who experiences it (Cohen, 2008). Story telling is argued to be the central means of human sense-making, retrospectively (Polkinghorne, 1988), as we construct and understand the world through stories (Bruner, 1990) to create a narrative identity (Ricoeur, 1988). It is assumed that our identities are informed and constrained by narratives of the local, historical and cultural context (Taylor & Littleton,

2006). Thus, narrative analysis enables a critical examination of the individuals' experience and the social influences involved rather than just the personal experience.

It was useful to adopt a dialogic/ performance analysis (Bamberg, 1997; Riessman, 2004) to explore a sense of who participants are and how they wish to be perceived at a particular time and context (Bamberg, 1997). A thematic narrative analysis (Reissman, 2008) was then used to explore 'how people make sense of their worlds' (Smith & Sparkes, 2009, p. 281) enabling consideration of how individuals make sense of the disruptions to normality, the influencing dominant narratives or social context and reflections on what identity is being constructed (Plummer, 2001).

2.1.1. Quality assurance

Researchers (Reissman, 2008; Yardley, 2000; 2008) have recommended criteria to ensure the strength of qualitative research including credibility (i.e. plausibility of interpretations), rigour (i.e. extent interpretations are supported by original data) and pragmatic usefulness. The following steps were taken to ensure these criteria were met. For credibility, the researcher has attempted to argue her position and chosen methodology by explicitly stating the justification for the research methodology and outlining the analytical process. A reflective journal has been recorded (Appendix 5) to encourage ongoing reflexivity about the impact of critical decisions in the process (Reissman, 2008). Whilst transcribing the interviews the researcher recorded non-verbal communication and the experience of the discussion. The results and interpretations were shared with the participants to ensure their intended meaning was analysed to minimise assumptions. The final results and interpretations are also grounded in the direct quotes from participants as a form of transparency to ensure

rigour. The clinical relevance of the study is discussed in the introduction and conclusion of the thesis to express the pragmatic usefulness of this research. In addition, the researcher intends to publish the research in a peer reviewed journal.

2.2. Participants

The study employed purposive sampling using a snowball method of recruitment. Participants were adults with a diagnosis of SCD who were employed or received benefits. All had attended or were in contact with a community based SCD support group in north and south London. A total of nine participants were interviewed to gather detailed and rich information; 5 women, 4 men, (mean age = 39.8) (Table 6).

Table 6. Participant demographics

<i>Name</i>	<i>Age</i>	<i>Gender</i>	<i>Diagnosis</i>	<i>Nationality</i>	<i>Employment status</i>
<i>Sharon</i>	22	Female	SC	Black African	Employed
<i>Joshua</i>	22	Male	SS	Black African	Employed
<i>Christina</i>	23	Female	SS	Black British	Employed
<i>Jackie</i>	31	Female	SS	Black British	Self- employed
<i>Chantel</i>	46	Female	SS	Black African	Employed
<i>Charles</i>	49	Male	SS	Black British	Unemployed
<i>Kenneth</i>	50	Male	SS	Black British	Unemployed
<i>Paul</i>	56	Male	SC	Black Caribbean	Retired
<i>Pauline</i>	60	Female	SS	Black British	Retired/ Volunteer

Note. Names used are pseudonyms.

The inclusion criteria were:

- *Aged 20-64.* Consideration was taken for the impact of the changing social context on the experience of the working population.
- *Worked or applied for jobs for at least 2 years.* Experience of working or attempting to get employment was necessary.

- *English speaking individuals-* This method relies heavily on language use so English was necessary to ensure the meanings of narratives were not lost through translation.

Participants were excluded if they had other health conditions not associated with SCD (e.g. Diabetes) or major traumas associated with SCD (e.g. organ failure) to explore the impact of primary SCD symptoms on the experience of those working.

2.3. Procedure

Facilitators of SCD support groups were contacted to discuss the project. Posters (Appendix 6) were placed around SCD support group venues and information sheets (Appendix 7) were left at the reception. The researcher then attended a SCD support group and presented the project including information regarding informed consent, confidentiality and right to withdraw to those in attendance. Time was allocated for questions and information sheets were provided. Interviews were arranged at times and locations convenient to participants (e.g. support groups). Before the interview a consent form and demographic questionnaire (Appendix 8) was signed. The recorded interviews ranged from 30 to 150 minutes. Participants discussed their interview experience and responses to the topic after the recording. Interviews were transcribed (Appendix 9). A summary of the study was sent to participants and ethics committee following the study's completion (Appendix 10 and 11 respectively).

2.3.1. Interview

The interview technique suggested by Jovchelovitch and Bauer (2000) was used. The interview was initiated by the researcher (Appendix 12) and the basic phases of the narrative interview are shown in Table 7. As suggested, questions were generated at the time of the interview to prompt expansion or continuation of participants' stories.

Table 7. Basic phases of the narrative interview (Jovchelovitch & Bauer, 2000)

<i>Phases</i>	<i>Rules</i>
<i>Initiation</i>	<ul style="list-style-type: none">- Formulating initial topic of narration- Using visual aids
<i>Main Narration</i>	<ul style="list-style-type: none">- No interruptions- Only non- verbal encouragement to continue story- telling- Wait for the coda
<i>Questioning phase</i>	<ul style="list-style-type: none">- Only 'what happened then?'- No opinion and attitude questions- No arguing on contradictions- No why questions- Exmanent questions (i.e. ones emerging from the researchers' background knowledge and interests as well as from the languages and vocabularies they use) into immanent questions (i.e. those which translate the researchers' knowledge and languages using only the words and expressions emerging from the interviewee's narration)
<i>Concluding talk</i>	<ul style="list-style-type: none">- Stop recording- Why questions allowed- Memory protocol immediately after interview

2.4. Analysis

Each transcript was analysed in turn. The researcher read each narrative several times to become immersed in the narrative alongside listening to the recordings. This provided information on the tone and interactions that may have been lost in the transcription process. Notes were made about the structure, performance and content. Structure and performance notes provided information for how the narrative was compiled to achieve the narrator's 'strategic aims' (Reissman, 2008, p.77), and insight into their experience of telling their story by focusing on the emotional content

underpinning the narrative. These developed a 'global impression' (Lieblich Tuval-Mashiach & Zilber, 1998) and summary of the main themes that arose from each account. Content notes identified the experiences recounted. They were compared to develop broad storylines (i.e. themes or positions) which emphasised the similarities and differences of the narrators' experiences. Tables were produced to describe storylines (Appendix 13). Excerpts reproduced in the results were 'cleaned up' (i.e. erase dysfluencies) but the stories remain intact (Reissman, 2008).

2.5. Ethics

The British Psychological Society code of Ethics and conduct (2006) was adhered to throughout the study. Ethical approval was received from the Salomons Ethics Committee (Appendix 14) at Canterbury Christ Church University.

3. Results

First, the results will provide a summary of the interview and 'global impression' (Lieblich, et al., 1998) for each narrative to provide the reader with a framework to position the interpretations and overall impressions. Then the overarching themes are presented; experiences influencing work engagement, experiences influencing relationships with work and experience of being unemployed. The subthemes emphasise the collective storylines emerging from the narratives. Quotes from participants are shown in italics.

3.1. Participants- Summary and 'global impressions'²

Sharon

Sharon is a 22- year- old who works for her mother in estates management but aspires to be an events planner. Sharon's interview occurred in a quiet warm clinic room.

Sharon's account is punctuated by short stories of her childhood and present days' experiences that enlightened her hopes and fears for the future. Sharon highlighted the importance of remaining healthy and resting to manage her condition but acknowledged the financial benefit that comes from having a good career. There is an air of isolation as everyone's experience of SCD is different, so there is a need to carve out your own path. Sharon's account is blunt and factual except when referring to the transition from dependence to independence particularly during university. Sharon's stories often positioned the researcher as a perpetrator due to their ignorance of the injustices experienced. Sharon displays persistence to overcome failure and achieve her cultural narrative of progression;

'no one wants to be less successful than their parents, do they? You want to sort of be just as- *or you know excel even more*'.

Joshua

Joshua is a 22- year- old who was due to start a new role but struggled with the unpredictable nature of his condition during the summer months. The interview was held in a quiet warm medical room. It was interrupted once at the end of the interview by centre staff.

²Names and occupations have been changed to ensure anonymity

A strong storyline was the need to defend and protect himself against others' opinions and perspectives to achieve his career goals. Joshua spoke about the conflicts of a 'protective' mother and inspirational father's positive work ethic highlighting his self-preservation.

'she wants me to go on benefits and be getting some sort of assistance... which isn't really to my taste... I'm a go-getter, I just want to go out there and work as hard as possible'

Joshua's account elicited strong emotions in the researcher as he reminisced about childhood bullies, the physical anomalies of SCD and the consequential impact on his confidence, becoming paranoid about the perceptions others held about him. These continuing prejudices in the workplace affected his mood and attitude to the organisation. Joshua's account seemed to illustrate a learning curve to developing a level of tolerance and resilience to cope with the prejudices of others.

Christina

Christina is a 23- year- old medical professional. Her interview occurred during one of her days off whilst waiting for a medical appointment in a quiet, warm room.

Christina's account presents a journey that is punctuated by stories highlighting her attempt to become independent in her role whilst managing her condition. The narrative emphasises her ever-changing relationship with her condition and the consequential impact on her mood and sense of self;

'As I've gotten older I've...self- harmed, I've done so many stuff... I just brushed it all under the carpet and then just had to deal with it and then obviously it erupted'.

Christina frequently normalised her experiences, particularly when referring to difficult aspects of her journey. Her account is punctuated with self- deprecating humour, comparisons to peers and disbelief of her career path. This narrative seemed to portray a battle of love and power; Christina persevered to align the needs of her condition with the values of the organisation through compromise. She highlighted the battle between '*rational*' thought of acknowledging the needs of the organization and the emotional yearning for the company to recognize her needs.

Jackie

Jackie is a 31- year- old entrepreneur. The interview was held during a period of good health and occurred in a quiet warm room.

Her account is light-hearted and served to engage in the performance of her stories (e.g. different voices, dancing). Jackie's account is constructed of events in her life that informed the listener that she was 'a warrior'. Her account placed high value on being '*a control freak*' not only of her condition but in the construction of how others perceived her. This leads to the assumption that her preferred position was to live 'normally' like her peers so, though she had encapsulated her SCD as an aspect of her identity she was not limited by it;

'there is a lot more to you than just that [SCD] and I refuse to live a life where I allow
that restriction to be the main thing in my life'.

Her crises were constructed as periods of weakness so recognising the triggers was empowering. Jackie used humour to heckle those who had belittled her abilities. Consequentially her experiences were constructed as opportunities to learn about who she is and reconstruct herself.

Chantel

Chantel is a 46- year- old who works in estate management. She was currently unable to work as her hip bone had cracked and was waiting for surgery. Chantel's interview was held in a quiet warm therapy room at the SCD support centre.

Chantel's narrative is punctuated with optimistic and positive stories about the benefits of educating others of the severity and unpredictable nature of the condition. Her account portrays an educator who flexibly adjusts to her environment. The emotional language used showed her passion for her role and colleagues. Chantel's account illustrates how her earlier experiences motivated her in adulthood to lead a normal life but be informed and cautious of factors that could impact on her health;

'my parents... they never stopped or encouraged me to sit back and not do anything.

I wasn't treated any different from anybody... health and education came first even before the illness'.

Charles

Charles is a 49- year- old who at the point of the interview had been living on benefits for approximately 10 years. The interview occurred following Charles' blood transfusion in a quiet room. Through the interview the heating would intermittently switch off causing Charles to experience a lot of pain so the interview was terminated.

Charles' narrative portrayed an optimistic tragedy. He recalled experiences of rejection/ failures in his career roles but his story illustrates a journey of perseverance and resilience. Charles is personable; his story at times disjointed as he processed

his experiences but they were punctuated with humour. They were presented to expose his lack of control, support and feelings of injustice;

'my manager told me she'd been pressured into finding ways to oust me for nothing more than having this condition, doesn't matter how much I tried... If I had holiday time I would use that to cover my period of sickness'.

Charles' narrative addresses the toll these experiences had on his body and character from the loss of life that he had aspired for. He drew on the dominant narratives of chronic illness and SCD and addressed the difference between ability and capability reckoning that they are often intertwined as a strategy to remove him from his position at work

Kenneth

Kenneth is a 50- year- old whose experience of work life had been unstable due to his condition. The interview was held in a quiet warm room.

Kenneth's narrative portrayed the identity of 'a survivor'; he described himself as 'stubborn' as he continued to pursue what he wanted despite any obstacle. He spoke passionately yet factually about his experiences and was confident in his work ability. Kenneth stressed the importance of being vigilant as his mode of surviving and emphasised his lack of interest in others' perceptions particularly if it was based on limited knowledge about SCD;

'most of them think like- time waster... there is no physical outward signs... they don't understand how you can be well one day or... minute and be unwell the next'.

His matter of fact language and style was broken intermittently with laughter to relieve the tension of his accounts and heckle at the attempts made to enforce control over his life.

Paul

Paul is a 56- year- old retired house husband who had worked manually. The interview occurred in a warm clinic room at the sickle cell society.

Paul was anxious and frequently checked throughout the narrative the relevance and appropriateness of his story. This linked to his uncertainty regarding the importance of his SCD in comparison to other presentations (i.e. SS); it also contextualised his experiences in regards to the restrictions resulting from poor technology and the societal discourses of men coping (e.g. stiff upper lip). His association with support groups was a turning point that developed his knowledge, framed his experiences and self- perception as a worker. Being retired is positioned as a welcomed new lease of life that enabled Paul to reduce the experienced stress and focus more of his time on his family. However, Paul identified strongly as a manual labourer and fought to retain this identity due to fear of being perceived as lazy;

‘they (colleagues) used to take the mick out me and say cor Paul you’re lazy ...they started giving me lighter jobs... At first I liked it but I got kind of bored; I was still
going and helping the guys when I could’.

Pauline

Pauline is a 60- year- old retired financier who now volunteers at the support group. Her interview took place in a warm medical room. The interview was interrupted twice by a SCD nurse during the questioning phase.

Pauline's account portrayed an identity of someone who had become more affiliated with her condition as she grew older. She emphasised the influence of family narratives in pursuing her career aspirations despite the implications to her health. Pauline's resilience is accentuated throughout her account in her demonstration of her ability to work and her adjustment to the obstacles encountered. Her stories portray 'a silent fighter'. Her inability to speak up for herself during work was a powerful contrast to her presentation in the interview. Pauline's account emphasises a change in priorities following retirement due to her condition worsening and cancer diagnosis. However, her volunteer role is framed as an experience that regained her control and strengthened her sense of self;

'I'd love to go back to work now cos I'd have something to say to those people cos I understand my illness... but at that particular time I couldn't deal with it so it was all stored in there [points to heart]'.

3.2. Thematic Analysis

3.2.1. Experiences influencing work engagement

All participants' attitudes towards work varied, and this seemed to be linked with their previous relationships with the education system, support implemented in transition to employment and experiences disclosing SCD. Their experiences regulated

expectations for the work environment and provided insight into their coping style and resilience.

The negative perception of teachers

Four participants briefly made reference to how aspects of their school life had impacted on their work identity development as their experiences in the school setting mirrored their career organisation system. Early low expectations from teachers either drove them to work harder to prove their ability or created a sense of hopelessness. Stress was a debilitating factor caused by pressure to attain the required academic results with frequent hospital appointments. A core narrative was the necessity to reconstruct teachers' low expectations of their ability and prove SCD was not an excuse for poor performance to preserve their positive self-perception and protect their psychological and emotional wellbeing. Jackie's language illustrated a robust knowledge of who she is and her capabilities which combatted the discriminatory and dismissing narratives of teachers;

Jackie: *'There was this underlying thing of... 'oh she's ill again'... 'this is just her standard of work'... which was unacceptable for me and I am the kind of person that [laughs] will push to do well to get something.'*

Charles' use of language when he described being 'cheated' out of better grades (i.e. 'at rock bottom') powerfully portrayed the importance of his education and the injustice in not achieving his potential. He expressed uncertainty at the extent racial discrimination contributed to these negative *preconceived ideas* held by teachers and later work colleagues. Yet, there was an inability to pre-empt or change these assumptions which added to the injustice, loss of power and control.

Charles: *'People look at me and the first thing they see is a black man, the fact that I'm a man doesn't make a difference'.*

Academia to work transition

Three individuals commented on how they perceived transition from academia to work life in regards to the preparation and support implemented to enable independent working in their chosen career. This experience was seen as impacting self-perception and their management of SCD. A core narrative was the necessity of regular breaks and hydration to reduce the physical strain on their body and the ease of transferring support from academia to work environments.

Christina- *'I fainted in theatres...all health related...it was different being a student ...when you're by yourself there's times you don't get a break... it's too much for my body to handle'.*

Sharon's language conveyed dismay at the lack of support received resulting in frequent crises and contemplation of alternative career options. In contrast, Christina and Chantel's accounts described the benefits of trialling effective working conditions and tutors who promoted the importance of support in academia. A positive transition from academia to the work environment strengthened participants' affiliation to their career as similarities were drawn between personal values and the values of the organisation. Yet, a false sense of security was created following negative transitions.

SCD was portrayed as an invader of their life and an obstacle to living normally; an emotional account by Christina exposed the fear and the consequential impact on her emotional wellbeing (*'making me feel depressed'*) of making a career choice mistake. Frustration was portrayed by Sharon at the lack of contemplation others make about the commute or the daily impact of the weather on her health;

Sharon: *'When things like weather can affect the condition it puts you off... it may pay well but I think my health is more important.'*

Having the impact of career challenges on health highlighted prior to applying were portrayed as empowering; as it created opportunities to make informed decisions about careers whilst considering the health implications. Sharing experiences and feeling listened to increased perceived ability to cope and confidence, creating internalised positive narratives for Chantel that being ill is ok.

Disclosure of condition

Disclosing their SCD status when applying for a job can be a thought-provoking decision for individuals, as it was experienced as influential on the employer's perceptions of the individual's ability to fulfil the role. As illustrated in the narratives, previous experience of disclosure informed whether they would disclose and how. Five participants spoke about their decision to disclose.

There was a strong common narrative of responsibility to disclose to employers and develop a coping strategy for the response. Positive experiences of disclosing as illustrated in Joshua's account strengthened his commitment and sense of security within his role;

Joshua: *'everyone was a team...I told him that I was ill before I got the job and he says you know what just do what you can and when you feel unwell just let me know and we can sort something out'*

It was apparent that resilience to rejection and/ or the value placed on others' perceptions were influential on decisions to disclose. In Sharon's account discussions of *security* illustrated her yearn for a normal life and disclosure as a potential barrier (e.g. challenge employers preconceived assumptions yet prove competence).

Sharon: *'They might do their research on it and then their like 'oh this might be a burden rather than an asset to the company'.*

This positioned control with the employer whereas in Kenneth's account disclosure was empowering. His matter- of- fact manner displayed a detachment that aided him to conclude rejection as the employer's loss. However, a string of rejections, in Charles' account, caused him to feel *depressed*, as similarly to Sharon his aspired future appeared unattainable. Charles reasoned with employer's hesitance to employ (*'to a point I understand cos they want some kind of consistency'*), possibly to reduce the perceived personal failure.

A common narrative was the need to prove their ability to work. Only Jackie's account portrays the desperation and how not disclosing SCD to her employers enabled her to get her *foot in the door*. Managing SCD within the boundaries of her short term contract the risk of being fired for not disclosing far outweighed the missed opportunity for an aspired career.

3.2.2. Experiences influencing relationships with work

In order to manage the unpredictable and unremitting nature of SCD, it seemed imperative for organisations' and individuals' principles to align to ensure security and commitment to the role. The following storylines suggest the meaning of this alignment of principles for participants' relationship with work.

Seeking support for work adjustments to manage health

Six participants reflected on their experience of accessing support and adjustments within their role to improve their management of SCD. In all the accounts being employed was valued highly despite the difficulties posed by SCD.

Sacrifice of health is powerfully described in Pauline's account, as she aspired to be like her father and was *saving to buy a house*. It stimulated strong feelings about the fragility of SCD and the obstacles it created to living normally particularly with the demands of her role. Similarly to Sharon in the 'Academia to work transition' theme, Paul displayed frustration at factors colleagues may take for granted. Accessing appropriate adjustments appeared to be a matter of negotiation and was more feasible depending on their position within the organisation. Chantel stressed the benefits of having transparent communication with employers and talks of explaining SCD as similar to other health conditions so employers will sympathise with her experience. However, her management position enabled delegation of tasks to colleagues during crises which may not be a freedom held by others, as in Christina's case. Christina powerfully illustrates how employers' complete control over accessibility to work adjustments creates a sense of hopelessness;

Christina- *'I've done everything they wanted me to do' and 'I don't know what else they really want me to do'.*

Opportunities for working flexible hours or from home were suggested as a remedy. As Jackie got older, triggers such as menstruating were unavoidable and increased the frequency of her crises. Her passionate account described how having her own business enabled her to have *regular breaks and be flexible* with her time (e.g. scheduling workload/ meetings). Reflecting on the independence provided by services

such as *Access for Work* brought new energy to Charles' account (*'I was able to manage myself'*). Their positivity illustrated a boosted self-esteem and confidence. It appeared vital to have flexibility and input into the management of their activities. There was a portrayed need for employees to do the right thing and use initiative to be perceived as competent.

Power over managing SCD whilst working also appears to be held outside the organisation. Paul's disgust emphasised frustration at his doctor's refusal to sign off the necessary time from work for his body to recover and the health complications suffered from repeated prescribed pain relief. Lack of knowledge about SCD led to a heavy reliance on the doctor, reducing his ability to advocate for himself. Similarly, lack of union support seemed detrimental to Pauline's physical and psychological wellbeing;

Pauline: *'I'd have the runs and want to vomit... I've had 33 blood transfusions in one visit that's how ill I was...thinking and overthinking... the mental state of you is bad'*.

She was exasperated by others' assumptions of her coping abilities without witnessing her experience.

Being an educator at work

As SCD is not as widely advertised and discussed in comparison to other chronic illnesses, individuals often need to educate others in the wider society about their condition to get their conditional needs met and request work adjustments. Three participants discussed their role as an educator at work.

Chantel and Kenneth stressed two important reasons for informing employers explicitly about the intricacies of their condition. The first reason was to create an

environment conducive to team work so pressure is relieved and support from colleagues during crises is provided;

Chantel: 'if I educate them about what sickle cell is and how it can actually affect you
then my work life can be a lot better'.

The second reason addressed legally that if they had told her employer about their condition then they would be able to go to tribunal if wrongfully dismissed. A common narrative was that employers are ill-informed about the usage of morphine to relieve pain and the impact on an individual's health. This can lead to conflictual relationships as unreasonable requests to repeatedly inform employers reduced valuable time for recovery. Narratives indicated a perceived lack of choice in how to keep the employer informed since negative assumptions may give rise to possible grounds for dismissal. Joshua became more determined to educate others as a form of regaining control. A core narrative was hope that employers realise their dedication to their role motivates them to work through their pain so, resilience developed through reframing offensive comments as a lack of understanding.

Joshua: *'People can't dictate my life...I have to become easier with people...keep reassuring them...if I am working through pain...I am interested in that job'*.

Relationship with colleagues

The accounts illustrated that participants' relationships with their managers and colleagues were influential on their experience at work. This theme encapsulates how six participants perceived their relationship with managers and colleagues and how their relationship may have changed during crises.

A core narrative suggests the unpredictable nature of SCD creates perceived unreliability in the wider organisational team, as during crises their workload was

completed by colleagues heightening stress and intolerance to participants' SCD. Sharon reflected on how this influenced her relationship with her mother as her manager; in sighting that despite colleagues understanding of SCD, stress may cause negative assumptions about the participant to form. Hence, when well, participants worked twice as hard to prove their ability and value to the organisation despite recognising it as detrimental to their health.

Paul: 'a lot of people thought I was putting it on *which was really hurtful...* it took me *a long time to get over it all*'.

Pauline expressed disbelief and described how being harassed in front of colleagues led to feelings of powerlessness and created a loss of identity. Negative regard of Joshua's racial identity was powerfully expressed as influential on his work ethic and motivation to abide with the organisations policies.

Pauline: '*I had to put up with a lot ...it made me withdraw...I wouldn't answer people I'd take their comments*'.

Charles' reflective recount was enlightening of how recognition from colleagues provided reassurance that he was not at fault but stressed colleagues powerlessness for fear of being penalised for whistleblowing. Chantel suggested that when colleagues can see past SCD they are more empathetic and provide mentorship. This support encouraged her personal development and career progression and increased her confidence and self-belief though there was still fear of being ostracised signifying a thin line between being accepted and rejected.

External sources of support encouraged employers to provide alternative activities when the participant was able to work but recovering from a crisis, as they held a level of power and respect in the eyes of the organisation. Joshua enthusiastically

recounted the benefits of having a GP letter support his need for adaptations at work and justify his sick leave. Access to a union relieved Paul's fear of being fired and acted as a source of *protection*. Conversely, Pauline's account identified that support for mental health difficulties may be more challenging, increasing isolation from colleagues and the wider organisation; reinforcing discourses of the individual as the problem and increasing expectations to work harder despite the impact to health.

3.2.3. Experience of being unemployed

Coercion to leave job

After a number of crises and health related sickness, employers were perceived to find a multitude of methods to fire or encourage the person to resign; three participants described their experiences.

It was apparent from all the narratives that there was an expectation for participants to cooperate with the organisations requests to provide information and work to the standard set in the organisations ethos. A battle of 'them and us' was portrayed and refusal to comply was a defence against the organisation's inflexibility and enforcement of power. A common narrative was participants' reference to lawyers when unfairly treated by employers to regain reassurance, power and strengthen self-concept. For Charles, advice from a lawyer reduced his feelings of isolation and confirmed the injustice felt. However, taking a case to tribunal was not recommended by everyone. Kenneth considered them a *waste of time*, proposing they delayed the inevitable. He had accepted the routine of being sacked but expressed disbelief at the methods used; though the variety appeared to boost his morale;

Kenneth: *'my immediate boss' assistant came to visit me [in hospital] ... I thought 'wow, I must be really important' ... for a couple of hours, we laughed and joked... as he's going... I open the card and it had printed across the inside 'your fired'. he said 'don't worry about your stuff we'll send it to you... [laughs]'*

To cope, Kenneth focused more on his ability to get rather than keep a job. His reflection implied that employees are dispensable rather than valued members of the team. Pauline described how her employers purposively made it difficult for her to work, increasing her stress levels and sabotaging her credibility; the stigma towards her race and condition was intertwined. Resilience was shown in participants' motivation to continue working beyond their job role to maintain their personal concept of self, though the impact on their psychological and emotional wellbeing was apparent.

Life on benefits

Life on benefits is often construed negatively in the media and wider society. Two participants describe their experience of receiving and living on benefits and the impact this had on their self- perception.

The narratives both suggest that living a life on benefits often results in a loss of self. Charles's account suggests that a person's job title constructs social judgements about the individual in society resulting in a loss of identity when receiving benefits;

Charles: *'to have society look at you as a leech... [exhales] I don't feel great in myself cos I think I've not really anything to offer I wonder what my father thinks...it's the hardest thing... your job defines the person you are... if you're not working you're looked down on'.*

In contrast, Jackie's account framed receiving benefits as a period of reflection. She portrays a drive to reap the benefits of life rather than *just existing*. Their stage of life in receiving benefits seemed influential of their differences in perspective due to the health implications on their ability to work. Charles also initiates as a male there are societal expectations for him to be a provider. His account indicates consequently he has become socially inadequate.

4. Discussion

In this section the researcher will present a summary of the study's findings in relation to the research questions and consider their clinical and research implications. The researcher will then critically review the methodological strengths and limitations and reflect upon my experiences of conducting the research.

4.1. Summary of findings

The primary aim was to explore the narratives a sample of people living with SCD construct to explain how the experience of employment impacts on their identity and retrospectively their quality of life.

How do a sample of people with SCD understand and construct their work identity?

Narratives illustrated participants' work identity is constructed to provide personal development, status in their family and community, financial independence and achievement of important life goals. Research (i.e. Blau et al., 1956; Baker & Donnelly, 2011; Heah Case, McGuire & Law, 2007) supports that early family narratives were

influential to their work ethic and school experiences sculpted their drive, resilience and engagement with organisations. All participants were passionate about their job roles, due to it being a 'claimed central character' (Walsh & Gordon, 2008). Their motivation to adapt and adjust their management of their condition in order to reduce their differences from colleagues was illustrative of most participants strongly developed work identity (Skorikov & Vondracek, 2011).

What are the core narratives used to describe the impact employment has on psychological wellbeing? What are the core narratives those with SCD use to describe the impact employment has on physical health?

A core narrative was the unpredictable and unremitting nature of SCD and the influence of this worsening and changing as an individual got older. The uncertainty of these factors led to increased stress, concerns about what their future may hold and a reformulation of their work identity (Rudman & Dennhardt, 2008; Braveman & Helfrich, 2001). The stress of applying, the inflexibility of organisations and losing a job was narrated as worsening most participants' physical health. However, these accounts demonstrated that the impact was also to participants' psychological and emotional wellbeing (Letkemann, 2002). Participants spoke about the double stigma of their race and SCD. In line with research (i.e. Royal, Jonassaint, Jonassaint & Castro, 2011), others' negative perceptions of their race influenced self-perception and affected their emotional, social and psychological wellbeing; subsequently affecting performance of work duties. Perceived lack of control over management of SCD at work also decreased psychological wellbeing (Thompson, Gil, Abrams & Phillips, 1992). Thus, a core narrative was the promotion of a healthy work- life balance in accordance to their conditional needs. Maintaining boundaries, managing SCD and a

sense of contributing acted as a defence mechanism, protecting participants' self-concept.

Are there common narratives participants use to describe their social and cultural experience of employment?

According to the narratives, participants contemplate the impact of the career on their health presently and in the future. A common narrative was the importance of having SCD experiences witnessed as it created a sense that the participant was part of the wider community. Support groups provided guidance and reduced isolation, developing participants' resilience to work challenges. Another common narrative related to lack of education about SCD and its management. Participants' role as educator within the organisation (Caird, Camic & Thomas, 2011; Campbell, Ross, Kumagai, Christner & Lypson, 2010), brought challenges but in some cases created empathy and positive relationships.

4.2 Methodological Considerations

The narrative analysis implemented for this study generated an in- depth insight into the heterogeneity of experience in living with SCD and constructing a work identity. Within the constraints of the word limit it was challenging to present the individuals and the rich data that portrays their experiences but I have attempted to be transparent in my methodological rigour to ensure trustworthiness and credibility in my interpretations. However, in line with my epistemological position the reader may generate different but equally valid interpretations as there is 'more than one way to interpret a text' (Ricoeur, 1976, p. 76).

The small sample size means it cannot be used to generalise experiences to all individuals living with SCD. Nonetheless, to ensure variation of experiences I have included a range of ages across adulthood, equal gender perspectives and individuals from different careers and points in employment. It is also important to consider that the majority of participants were selected from London support groups. London is very diverse in comparison to the rest of the UK and the support gained from these groups may have led participants to be more accepting of their condition and resilient to the negative perceptions of others.

The unstructured nature of the interview enabled some participants to reflect freely on their experiences whereas others found this challenging resulting in more guided and co-constructed narratives. Thus, some aspects (i.e. underlying reflections) of their stories may not be reported. It may have been beneficial to meet with participants more than once so they could become more comfortable with the process, share more stories and elaborate or elucidate hidden or partial stories. However, the timeframe of this research did not allow for this.

It was difficult during the interviews to not be a psychologist; offering reassurance and confirmation. Nonetheless, participants generally stated telling their story was cathartic and strengthened their sense of community as challenges were shared. I feel being a black female from a working class background in my late twenties impacted on the stories told. It is important to acknowledge that different stories and alternative identities may have been constructed with individuals from different gender, socioeconomic background and ages to myself.

4.3 Clinical implications

The findings illustrate the complexities of applying and maintaining a career whilst managing SCD due to its lack of understanding in the general population. As individuals feel they are positioned in society according to their employment status they strive to maintain a positive identity and live normally. Clinicians should develop a good understanding of earlier relationships with their support network and the wider society to gain insight into the narratives that construct their coping strategies and resilience to challenges. Participants used either self- other comparisons or detachment to maintain a preferred identity within organisations.

A keenness to share and have others witness and validate their experiences proposes the importance for clinicians to allow their story to be heard and reflect on the stigmatising narratives surrounding SCD. Particular attention is needed to factors at times of transitions (i.e. academia to work, loss of job) that impact individuals psychological, physical and emotional wellbeing such as negative assumptions. Support groups may provide information and guidance about their rights at work and access to services enabling informed choices about their management of SCD, reducing isolation and creating empowerment. This research advocated the use of a holistic person centred approach that ensures the biopsychosocial factors are addressed, implying that psychologists are essential to guarantee this is central to all facets of the individual's treatment.

4.4 Research implications

The nature of the study meant the sample size was small so, further research will be need to be repeated with a larger sample. Future research should also specifically examine highlighted aspects of experience at work for a more detailed understanding.

Future research may examine the support provided at schools to prepare individuals with SCD for employment such as disclosing their condition, influence of teachers' perceptions and opportunities to trial careers. This support may enable realistic perspectives of whether the career aligns with their needs/ values.

As the population of the participants for this study are from a black Caribbean or African background, future research may wish to explore whether there is consistency in the findings for individuals living with SCD from an Asian or Mediterranean background. This may be of particular interest the extent stigma and racial identity influence perceptions at work and generally.

5. Conclusion

The findings make an important contribution to understanding the experience of living with SCD and highlights the influences at work participants drew upon to construct their identity and quality of life. The joint consideration of what was told and how it was told enabled consideration of immediate and wider contexts of the narrative co-constructed which is crucial to building understanding.

Participants used the narrative format to question, interpret and reflect on their experiences engaging with work, their relationships with organisations and unemployment. These experiences were narrated as detrimental to participants' physical health, psychological and emotional wellbeing, social and cultural experience.

Power and control over the management of their condition appeared to mediate the impact of these experiences. Their resilience to challenges at work were developed from earlier experiences at school, values instilled from family narratives and their personal relationship with SCD.

The value of the narrative approach was demonstrated in the participants' personal construction of the content of the analysis. The small sample size limits the conclusions that can be drawn but this research highlights several important areas for consideration clinically and suggests further research in this field. It is hoped the dissemination of this research will contribute to the broadening general understanding of SCD and subsequently improving the experience of living with SCD.

References

- Abrams, M. R., Phillips, G., & Whitworth, E. (1994). Adaptation and coping: A look at a sickle cell patient population over 30- An integral phase of the life long developmental process. *Journal of Health & Social Policy*, 5 (3- 4), 141- 160. DOI: 10.1300/J045v05n03_09
- Adler, P. A., & Adler, P. (1988). Intense loyalty in organizations: A case study of college athletics. *Administrative Science Quarterly*, 33, 401- 417. DOI: 10.2307/2392716
- All Party Parliamentary Group. (2009). *The Social Aspects of Sickle Cell Disease and Thalassaemia in Children and Young people*. Retrieved from <http://www.dmu.ac.uk/documents/health-and-life-sciences-documents/sickle-cell/appgreportmarch2009.pdf>
- Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology*, 129, 723- 729. DOI: 10.1111/j.1365-2141.2005.05500.x
- Baker, K., & Donnelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society*, 16, 71- 85. DOI: 10.1080/713662029
- Bamberg, M. (1997). Language, concepts and emotions: The role of language in the construction of emotions. *Language Sciences*, 19, 309- 340. DOI: 10.1016/S0388-0001(97)00004-1
- Bamberg, M. (2004). Talk small stories and adolescent identities. *Human Development*, 47, 366- 369. DOI: 10.1159/000081039
- Bamberg, M. (2011). Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, 21, 3- 24. DOI: 10.1177/0959354309355852

- Barbarin, O. A., & Christian, M. (1999). The social and cultural context of coping with sickle cell disease: A review of biomedical and psychosocial issues. *Journal of Black Psychology*, 25, 277- 293. DOI: 10.1177/0095798499025003002
- Beatty, J. E., & Joffe, R. (2006). An overlooked dimension of diversity: The career effects of chronic illness. *Organizational Dynamics*, 35, 182- 195. DOI: 10.1016/j.orgdyn.2006.03.006
- Bediako, S. M. (2009). Psychosocial aspects of sickle cell disease: A primer for African American psychologists. In H. A. Neville, B. M. Tynes & S. O. Utsey (Eds.), *Handbook of African American psychology* (pp. 417- 427). Thousand Oaks, CA: Sage.
- Bediako, S. M. (2010). Predictors of employment status among African Americans with sickle cell disease. *Journal of Health care for the poor and the underserved*, 21, 1124- 1137. DOI: 10.1353/hpu.2010.0945
- Bediako, S. M., Lavender, A. R., & Yasin, Z. (2007). Racial centrality and health care use among African American adults with sickle cell disease. *Journal of Black Psychology*, 33, 422- 438. DOI: 10.1177/0095798407307044
- Blau, P. M., Gustad, J. W., Jessor, R., Parnes, H. S., & Wilcock, R. C. (1956). Occupational choice: A conceptual framework. *Industrial and Labor Relations Review*, 9, 531- 543. DOI: 10.2307/2519672
- Braveman, B., & Helfrich, C. A. (2001). Occupational identity: Exploring the narratives of three men living with AIDS. *Journal of Occupational Science*, 8 (2), 25- 31. DOI: 10.1080/14427591.2001.9686486

The British Psychological Society. (BPS, 2009). Code of Ethics and conduct. Leicester: BPS.

Retrieved from

http://www.bps.org.uk/sites/default/files/documents/code_of_ethics_and_conduct.pdf

Bruner, J. S. (1990). *Acts of meaning*. England, UK: Harvard University Press

Caird, H., Camic, P. M., & Thomas, V. (2011). The lives of adults over 30 living with sickle cell disorder. *British Journal of Health Psychology*, 16, 542- 558. DOI: 10.1348/135910710X529278

Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy*, 53, 547- 558. <https://www.aota.org/-/media/corporate/files/publications/ajot/slagle/1999.pdf>

Cohen, B. M. Z. (2008). *Mental Health user narratives: New perspectives on illness and recovery*. Basingstoke: Palgrave Macmillan.

Erikson, E. H. (1956). The problem of ego identity. *Journal of the American Psychoanalytic Association*, 4, 56- 121. DOI: 10.1177/000306515600400104

Erikson, E. (1968). *Identity, youth and crisis*. New York: Norton.

Feldman, D. C. (1988). *Managing careers in organizations*. Glenview, IL: Scott Foresman & Company

Fineman, S. (1979). A psychosocial model of stress and its application to managerial unemployment. *Human Relations*, 32, 323- 345. DOI: 10.1177/001872677903200405

Fraher, A. L., & Gabriel, Y. (2014). Dreaming of flying when grounded: Occupational identity and occupational fantasies of furloughed airline pilots. *Journal of Management studies*, 51, 926- 951. DOI: 10.1111/joms.12081

- Gabriel, Y. (2005). Glass cages and glass palaces: Images of organization in image-conscious times. *Organization*, 12 (1), 9- 27. DOI: 10.1177/1350508405048574
- Gil, K. M., Carson, J. W., Porter, L. S., Scipiro, C., Bediako, S. M., & Orringer, E. (2004). Daily mood and stress predict pain, health care use and work activity in African American adults with sickle- cell disease. *Health Psychology*, 23, 267- 274. DOI: 10.1037/0278-6133.23.3.267
- Gould, R. L. (1978). *Transformations: Growth and change in adult life*. Oxford, England: Simon & Schuster.
- Grant, M. M., Gil, K. M., Floyd, M. Y., & Abrams, M. (2000). Depression and functioning in relation to health care use in sickle cell disease. *Annals of Behavioral Medicine*, 22, 149-157. DOI: 10.1007/BF02895779
- Hall, D. T. (1976). *Careers in organizations*. Palisades, CA: Goodyear Pub Co.
- Heah, T., Case, T., McGuire. B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74, 38- 47. DOI: 10.2182/cjot.06.10
- Holland, J. L., & Nichols, R.C. (1964). Prediction of academic and extra- curricular achievement in college. *Journal of Educational Psychology*, 55, 55- 65. DOI: 10.1037/h0047977
- Jahoda, M. (1982). *Employment and unemployment: A social- psychological analysis*. Cambridge: Cambridge University Press.
- Jenerette, C., Funk, M., & Murdaugh, C. (2009). Sickle cell disease: A stigmatizing condition that may lead to depression. *Issues in Mental Health Nursing*, 26, 1081- 1101. DOI: 10.1080/01612840500280745

- Jovchelovitch, S., & Bauer, M. W. (2000). Narrative interviewing. In P. Atkinson, M. W. Bauer & G. Gaskell (Eds.), *Qualitative researching with text, image and sound: A practical handbook* (pp. 57- 74). London, UK: Sage.
- Kielhofner, G. (2002). *A model of human occupation: Theory and application*. Philadelphia: Lippincott Williams & Wilkins.
- Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice* (4th ed.). Philadelphia: F.A. Davis Company
- Kramer, R. M., & Brewer, M. B. (1984). Effects of group identity on resource use in a simulated commons dilemma. *Journal of Personality and Social Psychology*, 46, 1044- 1057. DOI: 10.1037/0022-3514.46.5.1044
- Latack, J. C. (1981). Person/ role conflict: Holland's model extended to role- stress research, stress management and career development. *Academy of Management Review*, 6, 89- 103. DOI: 10.5465/AMR.1981.4288014
- Lent, R. W., Brown, S. D., & Hackett, G. (1994). Toward a unifying social cognitive theory of career and academic interest, choice and performance. *Journal of Vocational Behavior*, 45, 79- 122. DOI: 10.1006/jvbe.1994.1027
- Letkemann, P. (2002). Unemployed professionals, stigma management and derivative stigmata. *Work, employment and society*, 16, 511- 522. DOI: 10.1177/095001702762217461
- Lieblich, A., Tuval- Mashiach, R., & Zilber, T. (1998). *Narrative Research: Reading, analysis and interpretations*. London: Sage

- Mael, F., & Ashforth, B.E. (1992). Alumni and their alma mater: A partial test of the reformulated model of organizational identification. *Journal of Organizational Behavior*, 13, 103- 123. DOI: 10.1002/job.4030130202
- Mael, F. A., & Ashforth, B. E. (1995). Loyal from day one: Biodata, organizational identification and turnover among newcomers. *Personnel Psychology*, 48, 309- 333. DOI: 10.1111/j.1744-6570.1995.tb01759.x
- Navar, S., & Stanley, M. (2015). Occupation adaptation as a social process in everyday life. *Collective and Evolutionary Perspectives of Occupation*, 22, 26- 38. DOI: 10.1080/14427591.2014.882251
- National Institute for Health and Care Excellence. (2012a). *Methods for the development of NICE public health guidance (third edition) Appendix G*. Retrieved from <https://www.nice.org.uk/article/pmg4/chapter/appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and-associations>
- National Institute for Health and Care Excellence. (2012b). *Sickle Cell acute painful episode: Management of an acute painful sickle cell episode in hospital*. Retrieved from <http://www.nice.org.uk/nicemedia/live/13772/59765/59765.pdf>
- Obodaru, O. (2012). The self not taken: How alternative selves develop and how they influence our professional lives. *Academy of Management Review*, 37, 34- 57. DOI: 10.5465/amr.2009.0358
- O' Reilly, C. A., & Chatman, J. (1986). Organizational commitment and psychological attachment: The effects of compliance, identification and internalization on prosocial behaviour. *Journal of Applied Psychology*, 71, 492- 499. DOI: 10.1037/0021-9010.71.3.492

- Parry, J. (2003). The changing meaning of work: Restructuring in the former coal mining communities of the South Wales Valleys. *Work, Employment & Society*, 17, 227- 246. DOI: 10.1177/0950017003017002001
- Phelan, S., & Kinsella, E. A. (2009). Occupational identity: Engaging socio- cultural perspectives. *Journal of Occupational Science*, 16, 85- 91. DOI: 10.1080/14427591.2009.9686647
- Plummer, K. (2001). *Documents of life 2: An invitation to critical humanism*. London: Sage
- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York.
- Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Fort Worth: Texas Christian University Press
- Ricoeur, P. (1988). *Time and Narrative* (3rd ed.). Chicago, IL: University of Chicago.
- Reissman, C. K. (1993). *Narrative Analysis: Qualitative Research Methods- Series 30*. California: Sage
- Riessman, C. K. (2004). A thrice told tale: New readings of an old story. In B. B. Hurwitz, T. Greenhalgh, & V. Skultans (Eds.). *Narrative research in health and illness* (pp. 309- 324). London: Blackwell. DOI: 10.1002/9780470755167.ch19
- Reissman, C. (2008). *Narrative Methods for the Human Sciences*. California: Sage
- Royal, C. D., Jonassaint, C. R., Jonassaint, J. C., & De Castro, L. M. (2011). Living with sickle cell disease: Transversing 'race' and identity. *Ethnicity & Health*, 16, 389- 404. DOI: 10.1080/13557858.2011.563283

- Rudman, D. L., & Dennhardt, S. (2008). Shaping knowledge regarding occupation: Examining the cultural underpinnings of the evolving concept of occupational identity. *Australian Occupational Therapy*, 55, 153- 162. DOI: 10.1111/j.1440-1630.2007.00715.x
- Sickle Cell Society (2008). *Standards for the clinical care of adults with sickle cell disease in the UK*. London: Sickle cell society. Retrieved from <https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCEQFjAA&url=http%3A%2F%2Fscct.screening.nhs.uk%2Fgetdata.php%3Fid%3D10991&ei=6UCVVdXmBsTZ-QHezavIBw&usg=AFQjCNGxIAgykNfzG2kkxug7RXHioNP3cA>
- Skorikov, V. B., & Vondracek, F. W. (2011). Occupational Identity. In S. J. Schwartz, K. Luyckx & V. L. Vignoles (Eds.), *Handbook of identity Theory and Research* (pp. 693-714). New York: Springer. DOI: 10.1007/978-1-4419-7988-9_29
- Smith, B., & Sparkes, A. C. (2009). Narrative analysis and sport and exercise psychology: Understanding lives in diverse ways. *Psychology of sport and exercise*, 10, 279- 288. DOI: 10.1016/j.psychsport.2008.07.012
- Taylor, S., & Littleton, K. (2006). Biographies in talk: A narrative- discursive research approach. *Qualitative Sociology Review*, 2 (1), 22- 38. <http://oro.open.ac.uk/id/eprint/4643>
- Thompson, R. J., Gil, K. M., Abrams, M. R., & Phillips, G. (1992). Stress, coping and psychological adjustment of adults with sickle cell disease. *Journal of Consulting and Clinical Psychology*, 60, 433- 440. DOI: 10.1037/0022-006X.60.3.433

- Unruh, A. M., Versnel, J., & Kerr, N. (2002). Spirituality unplugged: A review of commonalities and contentions and a resolution. *Canadian Journal of Occupational therapy*, 69, 5-19. DOI: 10.1177/000841740206900101
- Unruh, A. M. (2004). Reflections on: "So... What Do You Do?" Occupation and the Construction of Identity. *Canadian Journal of Occupational therapy*, 71, 290- 295. DOI: 10.1177/000841740407100508
- Walker, C. (2010). Ruptured identities: Leaving work because of chronic illness. *International Journal of Health services: Planning, administration, evaluation*, 40, 629- 643. DOI: 10.2190/HS.40.4.d
- Walsh, K. & Gordon, J. R. (2008). Creating an individual work identity. *Human Resource Management Review*, 18, 46- 61. DOI: 10.1016/j.hrmr.2007.09.001
- Warr, P., & Jackson, P. (1984). Men without jobs: Some correlates of age and length of unemployment. *Journal of Occupational Psychology*, 57, 77- 85. DOI: 10.1111/j.2044-8325.1984.tb00150.x
- Wells, K. (2011). *Narrative Inquiry*. Oxford: Oxford University Press
- World Health Organization. (2006). *Sickle- cell anaemia: Report by the secretariat*. Retrieved from http://apps.who.int/gb/archive/pdf_files/WHA59/A59_9-en.pdf
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228. DOI: 10.1080/08870440008400302
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 235- 251). London: Sage.

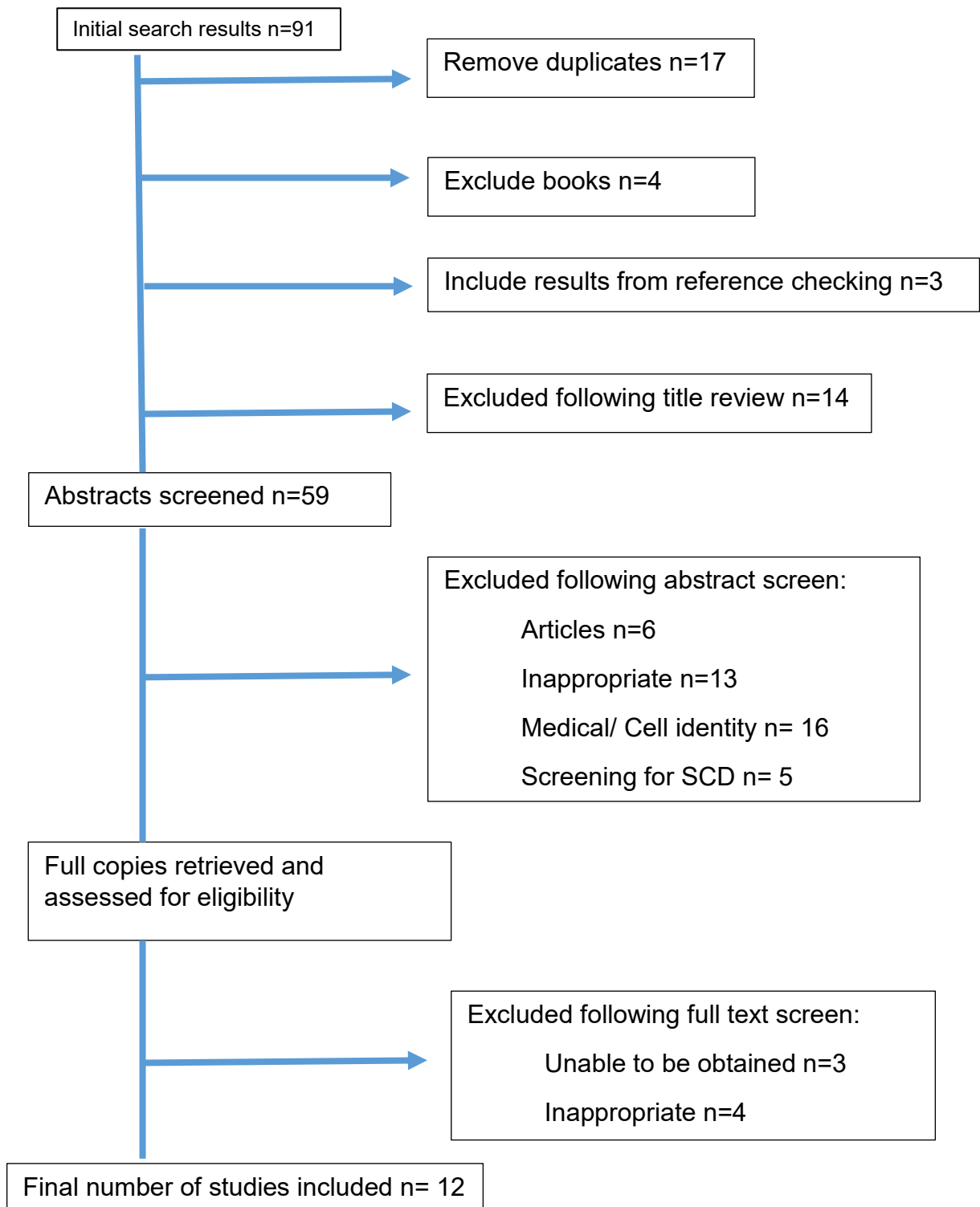
Major Research Project
Dominique Newsome BA (Hons), MSc

Section C

Supporting Information

Appendix 1: Search process

Flow diagram detailing paper selection process



Appendix 2: Article summary table

<i>Authors/ Year</i>	<i>Location</i>	<i>Sample details</i>	<i>Study design/ Method of analyses</i>	<i>Key findings</i>
<i>Lim, Welkom, Cohen & Osunkwo (2012)</i>	American	100 children; 8- 18yrs	Hierarchical linear regression, Chi squared, T- test	<ul style="list-style-type: none"> - Regard racial identity trended towards significance in moderating the relationship between pain and physical quality of life. - Regard racial identity did not moderate the relationship between pain and the other quality of life dimensions. - Pain significantly predicted all dimensions of quality of life. - Regard racial identity significantly predicted social quality of life.
<i>Lemanek, Horwitz & Ohene-Frempong (1994)</i>	American	59 children (10 females); 4yrs 1mth to 7yrs 10mths	One way ANOVAs, T- test, Pearson product-moment correlations	<ul style="list-style-type: none"> - No difference in parent and teacher ratings of social competence and behaviour problems. Scores from parents and teachers were also similar in children with SCD and the comparison groups. - Parents rated higher social skills than healthcare staff in children with SCD but no difference between parent and teacher ratings. - No significant difference in relationship between social competence and self- perceptions between children with SCD and controls or within groups. - No difference found in self- perceived competence and acceptance.
<i>Royal, Jonassaint, Jonassaint & Castro (2011)</i>	American	46 adults (26 females); 18- 56yrs (M= 32.04yrs)	ANOVA correlations	<ul style="list-style-type: none"> - Racial identity not related to disease severity or hospitalisations. - Public regard beliefs were negatively associated with parent's perspective that SCD influenced how others perceived and treated them. - Centrality of race and a nationalist ideology were positively associated with parent's belief that their race influenced their SCD experience. - There is a complexity of the interplay between racial identity beliefs and patients SCD experiences as well as the role of race in these experiences.
<i>Bediako, Lavender & Yasin (2007)</i>	American	83 adults (49 females); 18- 64yrs	Correlational analysis	<ul style="list-style-type: none"> - Significant path coefficients observed between pain severity, perceived stress and psychological symptoms. - SCD adults who reported more frequent pain episodes tended to use more health care services. - SCD adults who had high centrality with their race utilised fewer health care services. - Reported less severe pain episodes when being black is central to their self- concept.

<i>Bediako & Neblett (2011)</i>	American	83 adults (42 females); 18- 64yrs	Correlational analysis	<ul style="list-style-type: none"> - Individuals with SCD that are able to draw upon the social and psychological resources that reduce the negative impact of SCD experience better overall adjustment. - Multiple mediation analyses controlling for age and pain severity indicated the relationship between optimism and stress was unaffected by afrocultural ethos. - Inverse relationship between optimism and stress. - Optimism significantly associated with positive affect and spirituality.
<i>Caird, Camic & Thomas (2011)</i>	England	15 adults (11 females); 17- 68yrs	Grounded Theory	<ul style="list-style-type: none"> - Physical, psychological and social functioning adversely affected by SCD. - Access to and quality of resources are affected by their management of disorder. - As condition is accepted, management of condition improves. - Resilience strengthened through creating meaning, developing identity, actively coping with effects of SCD.
<i>Campbell, Ross, Kumagai, Christner & Lypson (2010)</i>	American	17 young people (9 females); 12- 28yrs	Phenomological inquiry method	<ul style="list-style-type: none"> - Belief in the ignorance of SCD by others including healthcare professionals. - Development of the identity of 'patient as teacher' to reduce medical errors, but this results in a change of power dynamics with medical staff. SCD patient becomes frustrated when information of care is withheld. - Teachers hold negative beliefs about condition such as SCD is an excuse to avoid mandatory activities. - Medical staff discount pain due to lack of objective confirmation of its presence. They often claim SCD sufferers are narcotic abusers. - Reduced public awareness about SCD.
<i>Sankar, Cho, Wolpe & Schairer (2006)</i>	American	22 adults (13 females); 18- 53yrs	Thematic analysis- Semi- structured Interviews	<ul style="list-style-type: none"> - Genetic cause of condition provides a positive focus for the person with SCD's sense of responsibility and control over the condition. - Condition provides protection from other disease, malaria. - Acquaintances are relived at condition being genetic as it is then not contagious but negative reaction from acquaintances as SCD signals flaw in respondent's family.
<i>Atkin & Ahmad (2001)</i>	England	26 adolescents (14 females); 10- 19yrs (M= 14.2yrs)	Interviews	<ul style="list-style-type: none"> - Coping occurred in dynamic space involving negotiation and engagement with both personal and structural factors. - Individuals with SCD develop a positive self- identity through recognition that it is a natural response for their illness to be difficult to cope with. May compare themselves to those with worse conditions.

Thomas &
Taylor (2002)

England

17 HbSS
young people
and adults (10
females)
15- 35yrs

Phenomological
inquiry method

- Having SCD complicates growing up and life transition but does not fundamentally alter it. Difficulties living with illness increases from 12 years old.
- Concerns about the future and repeatedly questions 'why me' as child gets older. It is beneficial for child to focus on here and now and have some medical knowledge of their condition.
- Play down the negative aspects of the condition for positive framing, to regain their sense of control over the condition.
- Family members facilitate individuals coping.
- Individual's relationship with faith is complicated and it is often utilised when needed.
- Social support was a valuable coping resource particularly for girls and younger children.
- Young children felt general ignorance was often experienced by wider social network but older children had learnt to accept this ignorance and so were less affected by it.
- Value was placed on social skills and empathy of health care professionals but their lack of knowledge was a major problem.
- Illness affected academic progress and felt teachers had 'written them off'.
- Perception that racism disadvantaged them in addition to the discrimination received regarding their condition.
- Six themes were identified to illustrate how SCD impacts on the quality of life:
 1. Growing up with SCD- parental reactions to condition, impact on friendships with peers, recognition of shortened life span, physical manifestations of condition.
 2. Education- consequences of absences, support from teachers, performing at academic ability though in pain.
 3. Impact of unremitting nature of the disease- coping with conditions unpredictability, undermines achievement and living normally, thoughts about the future, feelings of restriction.
 4. Employment- financial and social implications, disclosing condition, proving sickness, employer's response to condition, impact of not performing to best ability.
 5. Effects on relationships- impact on partners and relatives, difficulty relating to others, isolation, disclosing condition, limitations to lifestyles from condition.

				6. Hospitalisation- dislike being in hospital, unhelpful attitudes of staff, feelings of anger and frustration, lack of empathy, individual differences in coping and distraction techniques.
<i>Dyson, Atkin, Culley, Dyson, Evans & Rowley (2010)</i>	England	113 young people; 4- 25yrs	Mixed Methodology- survey and interviews	<ul style="list-style-type: none"> - Pupil and teacher knowledge of SCD not statistically associated with better treatment of young person in school - Most young people favour disclosing as teachers know how to react during periods of illness and make allowances for illness and absences. - The minority of young people with SCD found disclosing unhelpful as it attracts unwarranted attention or disabling attitudes. - Tension is experienced for the young person between acknowledging the reality of SCD and not wanting it to be a central part of their identity.
<i>Barbarin (1999)</i>	American	77 children with SCD; 74 control children; 5- 18yrs	Mixed Methodology- surveys and interviews Matched control group on age, race, gender, mother's marital status and socioeconomic status.	<ul style="list-style-type: none"> - As SCD increasingly interfered with normal living it meant greater risk of psychological dysfunction. - Emotional wellbeing of parents moderated adverse effects of SCD on children. - SCD affected activities they participated in due to stigma and infantilisation from family and friends. - SCD reported higher levels of support than control group. - SCD adolescents have integrated religious interpretation into their paradigms about the aetiology of the condition. This supports efforts to regulate their emotional reaction to pain and life disruption caused by the condition.

Appendix 3: Study quality checklist

NICE Quality Appraisal checklist (2012)

‘This has been removed from the electronic copy’

Yardley's (2000) 4-point model

'This has been removed from the electronic copy'

Appendix 4- Authors guide for submission to British Journal of Health Psychology

Author Guidelines

'This has been removed from the electronic copy'

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

Appendix 5: Reflective Journal

Thoughts about research in relation to theories

This research is informed by the belief that previous research is limited in capturing the narratives of developing an occupational identity whilst living with an unpredictable, unseen chronic illness. The exploratory focus of the research sought to capture the diversity of individual's experience. This postmodernist position highlights the multiplicity of experience that is of value in this research. It suggests that there is no one objective reality that is consistent and able to be measured. It is not considered possible to 'give voice' as suggested by the popular notion as we do not have 'direct access to another's experience... [and yet] deal with ambiguous representations of it-talk, text, interaction and interpretation' (Reissman, 1993; p. 8). Qualitative methodology enables a 'thick description' (Geertz, 1973) of people's experiences to be heard. A postmodernist framework enables the local narratives that do not fit with meta- narratives as well as the multiplicities of meanings and interpretations within a story to be considered.

Drawing on constructivist ideas this research adopted a position that though individuals know their own experiences, there are multiple realities and no absolute truth (Burr, 1995) as narratives are influenced by interactions, social locations and personal and societal values (Witten, 1993). It is important to consider that as realities are socially as well as personally constructed, the wider socio- cultural context in which personal stories are produced and heard must be understood (Burr, 1995). This research proposes that identity construction is based on the individual's self-perception and the perception of others, though the stories are collected from individual participants it is believed that their story is based on multiple voices (e.g. voices of family/ friends, interwoven social and political narratives (Frank, 2012)). Thus, the researcher is interested in how the individual draws on and/ or resists cultural narratives in relaying their experiences.

Another epistemological assumption is that stories are co-constructed, influenced by the assumptions and biases of the participant's (e.g. their views of the researcher (Goodley, 1996) or the researcher and audience as there are 'more than one way to interpret a text' (Ricoeur, 1976, p.76). Consequently, the narratives are considered temporally specific (Pearce, 2009).

Speculations along the way

Reflective bracketing enabled me to consider the implications of my personal value system on the research. Having close family and friends who are living with sickle cell disorder gave me an insight into the difficult experiences encountered in daily activities, not just physically but also socially. However, as they are children and adolescents, I was curious about how these experiences influenced their identity and future. The topic's importance became apparent in the initial stages of consideration when I realised that many people were unaware of the condition despite its prevalence increasing. I was more intrigued by this area of 'unseen' conditions following my road traffic accident, which resulted in me being labelled physically disabled. I found it difficult to negotiate public perceptions as I visually appeared physically able so, requesting a seat on a train was met with conflict as it wasn't visually noticeable why I

may struggle to climb stairs or walk short distances without severe pain if I had no crutch or my leg brace. This experience also heightened my recognition of my relationship to help and evaluate my values that affected my ability to request help.

In planning this project, I considered the challenges I may encounter in completing the project. I considered that if members of the sickle cell society did not feel that I had their best interests at heart gaining access to participants would be difficult. I considered the impact of my race, class and gender on the assumptions made by participants and in the co-construction of the stories told how these factors may be influential. In regards to my race, I presumed that participants may find it easier to discuss but also make assumptions about the extent of my understanding of the political and social impact of being Black in today's British society. I considered that my position as a Trainee Clinical Psychologist may lead to presumptions that I hold a middle class status. As a result, some may consider that I have a level of power similar to employers which could influence the relationship I develop with them in the interview. I also considered how being a woman may impact male participant's willingness to discuss certain aspects of their career experience such as their role in the family as the breadwinner through concern of how I may respond to that. At the time of starting this project, the scapegoating of those who live on benefits, increasing unemployment and challenges of working on a zero-hour contract were hot topics, particularly preceding the May 2015 elections. I was curious about the impact of the wider societal narratives on participant's narratives. I considered that this may have an impact on how participants react and respond to the topic, method and myself.

Development of ideas and observations

In recognising my attachment to the research, I considered how much my assumptions would influence the interviews. I felt that the narrative approach proposed by Jovchelovitch and Bauer (2000) enabled the least influence of my assumptions on the findings. I initially wanted to explore life on benefits for individuals living with sickle cell disorder but was made aware my external supervisor and one individual from a support group that employment experience generally is influenced by the SCD and widening the scope could provide more information about their quality of life and identity development into adulthood.

After discussions with my internal supervisor it felt important to report the position of each participant as a global impression to explore the influence of co-construction. I considered how being a psychologist may affect my response to stories of injustice and distress and gave myself a space after each interview to reflect on my experience of being with that participant. I was also aware that there was a strong pull to become a part of the support group and their events and negotiating boundaries to remain neutral was challenging as it affected the relationship I had with potential participants and staff at the centre. It was apparent that the support group functioned like a family and there was an overwhelming amount of resilience within the group but also an underlying powerlessness.

MY STORY, MY IDENTITY AND MY RELATIONSHIP WITH WORK



Hello

My name is _____.

I am a Trainee Clinical Psychologist at Canterbury Christ Church University.

I would like to invite you to take part in my research study.

Before you decide it is important that you understand why the research is being done and what it would involve for you. Please take time to read the information sheet at the reception desk.

Who: Aged 20- 64 diagnosed with Sickle Cell

Cost: Your travel costs will be reimbursed (up to £10)

This is an opportunity to tell your story...!

The aim of this study is to understand from your perspective how your experience of employment has affected how you see yourself, impacted your quality of life and physical wellbeing.

If you would like to speak to me and find out more about the study or have questions about it, you can leave a message for me on a 24-hour voicemail phone line at **0333 011 7070**. Please say it is for _____ and leave a contact number.

Appendix 7: Participant information sheet

My story, my identity and my relationship with work: Sickle Cell Disorder

Information Sheet

Hello. My name is _____ and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

Current research focuses on the onset of a chronic illness after developing a career, and the impact the loss of that career has on a person's identity, quality of life and physical wellbeing. There is limited research on the impact on an individual's education and later career choice if they were born with a chronic illness, particularly sickle cell disorder.

The aim of this study is to understand from the perspective of an individual who has Sickle Cell disorder (i.e. a chronic illness from birth) how they perceive their relationship with work has affected them.

Why have I been invited?

As a person aged 20-64 years with Sickle Cell disease:

- Who has worked or is working but had a number of periods out of work as a result of your illness
- Or: Who is currently out of work because of your illness
- Or: Chose to leave work/ not work

You are invited to take part in this study to understand your relationship with work and your identity (how you see yourself). I am hoping to have 6 participants who have been recruited from the Sickle Cell Society.

Do I have to take part?

No. It is up to you to decide. As this area of research has not been studied previously your experiences and perspectives would be highly valued. However, this study is entirely voluntary and refusal or withdrawal will have no penalty or loss, now or in the future to your service of care. It is up to you to decide whether or not to join in the study.

If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving reason.

What will happen to me if I take part? What will I have to do?

It is anticipated that the interview could take about 90 minutes. You will be asked to fill in a demographic questionnaire (e.g. age, gender and ethnicity). I will explain the main points of the discussion and give you the opportunity to tell me the most memorable parts of your story that describe your relationship to work and how you feel it may have affected the way you see yourself. I will then ask you a few questions if there are any points that I would like you to clarify or expand on. If you are happy to meet at a later date, we can talk together about the results generated from the study before it is finalised to ensure you are happy with your story. I can then give you a summary report of the final results.

The interview will be audio recorded. These will be made anonymous, encrypted and stored on password protected computers to ensure confidentiality. After completion of the project the audio

recordings will be erased. The written transcript of your interview will be stored on a password protected CD in Salomans Campus centre's office in a locked cabinet for 10years, after which time it will be destroyed. When interview recordings written down, names of people and places will be changed or disguised to preserve your anonymity.

Results will be written up in journals and individual data presented will be totally anonymous, without any means of identifying the participants involved. Data collected during the course of the project may be used for additional or subsequent research, but your details and stories/narratives will remain anonymous, if you give consent for this. Anonymous quotations from your interview may be used in published reports, along with those from other interviews.

Expenses- Your travel costs will be reimbursed up to £10. Please provide your receipts.

What are the possible disadvantages and risks of taking part?

Some participants may find the topic of conversation highly emotive or difficult to talk about. You will be given the opportunity to opt- out at any point in the process and afterwards, or state what you do not feel comfortable talking about, without giving a reason. If any distress is experienced from taking part in the project you can contact myself on the number below and a referral can be made to your local services if this would be helpful.

What are the possible benefits of taking part?

We cannot promise that the study will help you but the information we get from this study could help improve the treatment of people with Sickle Cell disease.

We hope that the project will provide employers, social services and medical professionals with a better understanding of the condition.

Your stories would provide clinical psychologists with a vivid understanding of the resilience and difficulties faced by people with Sickle Cell disease. They can use this information to be better advocates for people with Sickle Cell disease in medical and occupational teams.

Who is organising and funding the research?

The project will be funded by the Clinical Psychology Doctoral Programme, Canterbury Christ Church University, Salomons Campus.

Who has reviewed the study?

All research carried out as part of clinical psychology training at Canterbury Christ Church University is looked at by the Salomons Ethics Panel, to protect your interests. This study has been reviewed and was given favourable opinion on 9th February 2015

Contact details

If you would like to speak to me and find out more about the study or have questions about it, you can leave a message for me on a 24-hour voicemail phone line at 03330 117070.

Please say that the message is for me, _____ and leave a contact number so that I can return your call.

If you agree to be interviewed you can also call me on the number above so we can arrange a suitable time and place for the interview to take place.

Appendix 8: Participant Consent form and demographic questionnaire

Consent form

Title of Project: My story, my identity and my relationship with work: Sickle Cell Disorder

Researcher: _____

Please read and tick the statements below:

- I confirm that I have read and understand the Participant Information Sheet (dated 1/4/15; version 2) for the above study. I have had the opportunity to consider the information, as questions and have had these answered satisfactorily ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time up until the project is written up (data is stored anonymously and so it will be difficult to identify to remove the data after this stage) without giving any reason. ☐
- I understand that all personal information will remain confidential. I agree that my interview may be audio recorded and transcribed; my name and personal details will be changed during transcription to ensure I cannot be identified. ☐
- I agree that data gathered in this study may be stored anonymously and securely for 10 years ☐
- I agree that data gathered in this study may be used for future research ☐
- I agree that anonymous quotes from my interview may be used in published reports of the study findings ☐
- I agree to take part in the above study ☐

Name of the participant _____ Date _____

Signature _____

Name of Researcher _____ Date _____

Signature of researcher _____

Demographic Questionnaire

How old are you? _____

What is your gender? ☐ F ☐ M

How would you classify yourself?

☐ White British ☐ White Irish

☐ White Other _____

☐ Black British ☐ Black Caribbean ☐ Black African

☐ Black Other _____

☐ Indian ☐ Pakistani ☐ Bangladeshi

☐ Asian Other _____

☐ Chinese ☐ Chinese Other _____

☐ Mixed- please specify: _____

☐ Other- please specify: _____

Please specify your type of sickle cell disorder: _____

Appendix 9: Example Transcript

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

‘This has been removed from the electronic copy’

Appendix 10: Summary of study for participants

Dear [participant's name],

I hope this letter finds you well. I am getting in touch with a final update on my research project looking at the experience of employment when living with sickle cell disorder (SCD). Over the past months I have been analysing the interviews. I would like to provide a summary of these findings and also invite you to provide feedback.

The questions I set out to answer were:

- How do those with SCD understand and construct their work identity?
- What are the core narrative used to describe the impact employment has on psychological wellbeing?
- What are the core narratives those with SCD use to describe the impact of employment has on physical health?
- Are there common narratives participants use to describe their social and cultural experience of employment?

I have put my ideas and themes I found below. I have also used direct quotes from people interviewed in the project (these quotes may be from you) to help illustrate my ideas.

Theme: Experiences influencing work engagement

This theme was about how attitudes towards work varied according to previous relationships in childhood and adolescence. These experiences regulated expectations of the work environment and provided insight into their coping style and resilience.

The negative perception of teachers

Participants made reference to how their school life had impacted on their work identity development as their experiences in the school setting mirrored their career organisation system. For some people the earlier low expectations of teachers acted as a motivator to prove their ability. Participants displayed a strong, positive sense of self which protected them against the negative assumptions of teachers (*'There was this underlying thing of... 'oh she's ill again'... 'this is just her standard of work'... which was unacceptable for me and I am the kind of person that [laughs] will push to do well to get something.'*). It was felt that racial discrimination contributed to teacher's negative assumptions but there was uncertainty at the extent of its influence. Comments were made about the stress experienced from trying to attain the required academic results whilst managing frequent hospital appointments.

Academia to work transition

The academia to work transition reflected on how the preparation and support implemented at school enabled independent working in their chosen career. Less support or poor transfer of resources caused participants to consider alternative career options and created a false sense of security in the role. Whilst a positive transference of resources strengthened affiliation to the career. There were concerns about managing poor health with the responsibilities of their job roles in regards to the

consequences of making mistakes and the challenge of time keeping when factors such as the weather can affect their health. Being informed about these possible career challenges prior to applying enabled participants to make informed decisions with consideration to the implications to their health (*'When things like weather can affect the condition it puts you off... it may pay well but I think my health is more important.'*).

Disclosure of Condition

Whether to disclose SCD to potential employers appeared to be a thought-provoking decision informed by prior experience. For some participant's disclosure was empowering as they could clarify how the job role may impact their health and their capabilities. Positive experiences of disclosing strengthened commitment and sense of security in the role (*'everyone was a team...I told him that I was ill before I got the job and he says you know what just do what you can and when you feel unwell just let me know and we can sort something out'*). Though, others felt employers just relied on their negative assumptions of SCD and it reduced their chances of getting the job and living a normal life. Perceiving the rejection of a role as an employer's loss served to protect participant's identities. Alternatively, non-disclosure despite the risk allowed participants to prove their ability and not miss an opportunity at an aspired career.

Theme: Experiences influencing relationship with the organisation

To manage the unpredictable and unremitting nature of SCD it seemed imperative for organisations and individual's principles to align to ensure security and commitment to the role.

Seeking support for work adjustment to manage health

Accessing support and adjustments within their role to improve their management of SCD was challenging for most participants. Discussions about the sacrifice of their health to live normally illustrated the fragility of SCD and the obstacles it created. Lack of control over access to support was found to create a sense of hopelessness (*'I've done everything they wanted me to do' and 'I don't know what else they really want me to do'*). Transparent communication with employers, being in a management position, having their own business and access to services such as *Access for Work* were beneficial in creating flexibility over activities and independence in managing their condition. Poor external support (e.g. GP, union) had detrimental impacts to participants physical and psychological wellbeing (*'I'd have the runs and want to vomit... I've had 33 blood transfusions in one visit that's how ill I was...thinking and overthinking... the mental state of you is bad'*).

Being an educator at work

As SCD is not widely advertised and discussed, individuals often need to educate others at their organisation. Some participants felt that informing employers explicitly about the intricacies of their condition was important as it created an environment conducive to relieve team work pressure (*'if I educate them about what sickle cell is and how it can actually affect you then my work life can be a lot better'*) and legally they could go to tribunal if wrongfully dismissed. Conflictual relationships developed

following unreasonable requests and there was a perceived lack of choice in how to keep employers informed. There was hope that employers would recognise participant's motivation to work and so resilience developed by reframing offensive comments as a lack of understanding.

Relationship with managers and colleagues

Participants commented on how their relationship with managers and colleagues influenced their experience at work. The unpredictable nature of SCD was often perceived by members of the wider team as unreliability and heightened their intolerance due to increased workload pressure (*'a lot of people thought I was putting it on which was really hurtful. I think it took me a long time to get over it all'*). Participants worked twice as hard when well to prove their value to the organisation despite recognising its detriment to their health. Harassment and negative regard of race led to feelings of powerlessness and decreased motivation to abide with organisations policies. Support from the organisation encouraged personal development and career progression. Support from external agencies (e.g. GP, union) encouraged employers to provide alternative activities during periods of recovery and ill-health.

Theme: Experience of being unemployed

Coercion to leave job

After a number of crises and health related sickness, employers were perceived to find a multitude of methods to fire or encourage the person to resign. The narratives portrayed an expectation for participants to cooperate with the organisations requests for information. Most participants referred to lawyers for guidance and reassurance which strengthened their self- concept. For some taking a case to tribunal however was considered a *waste of time* as it delayed the inevitable. Working within a challenging environment where employers coerced participant's out of their role had a detrimental impact to their physical, psychological and emotional wellbeing.

Life on benefits

Living on benefits is often construed negatively in the media and wider society. The narratives illustrated that receiving benefits often resulted in loss of self as job titles construct social perceptions (*'to have society sort of look at you as though you're a leech... [exhales] I don't feel great in myself as a person cos I think I've not really anything to offer I wonder what my father thinks...it's the hardest thing... your job defines the person that you are... if you're not working you're really looked down on'*). Receiving benefits was also considered as a period of reflection to reconstruct their identity as a worker.

What next....

I would like to find out what you think of the results. I would be really grateful if you could let me know if you think the themes and ideas fit with your experiences of work as a person living with SCD. I hope this research will be used to improve and better

understand the experience of other people with sickle cell disorder at work. Please email me on d.newsome95@canterbury.ac.uk

Or call me on 0777 232 8678

Finally, I would like to thank you for taking the time to participate in this research project. It was a privilege to hear your stories which provided incredibly thoughtful ideas and explanations.

Warm wishes,

Dominique Newsome

Trainee Clinical Psychologist

Appendix 11: Summary of study for ethics committee

Dear Ethics Panel,

I hope this letter finds you well. I would like to provide a summary of the findings on my research project looking at the experience of employment when living with sickle cell disorder (SCD).

The questions I set out to answer were:

- How do those with SCD understand and construct their work identity?
- What are the core narrative used to describe the impact employment has on psychological wellbeing?
- What are the core narratives those with SCD use to describe the impact of employment has on physical health?
- Are there common narratives participants use to describe their social and cultural experience of employment?

I have put my ideas and themes I found below. I have also used direct quotes from people interviewed in the project to help illustrate my ideas.

Theme: Experiences influencing work engagement

This theme was about how attitudes towards work varied according to previous relationships in childhood and adolescence. These experiences regulated expectations of the work environment and provided insight into their coping style and resilience.

The negative perception of teachers

Participants made reference to how their school life had impacted on their work identity development as their experiences in the school setting mirrored their career organisation system. For some people the earlier low expectations of teachers acted as a motivator to prove their ability. Participants displayed a strong, positive sense of self which protected them against the negative assumptions of teachers (*'There was this underlying thing of... 'oh she's ill again'... 'this is just her standard of work'... which was unacceptable for me and I am the kind of person that [laughs] will push to do well to get something.'*). It was felt that racial discrimination contributed to teacher's negative assumptions but there was uncertainty at the extent of its influence. Comments were made about the stress experienced from trying to attain the required academic results whilst managing frequent hospital appointments.

Academia to work transition

The academia to work transition reflected on how the preparation and support implemented at school enabled independent working in their chosen career. Less support or poor transfer of resources caused participants to consider alternative career options and created a false sense of security in the role. Whilst a positive transference of resources strengthened affiliation to the career. There were concerns about managing poor health with the responsibilities of their job roles in regards to the consequences of making mistakes and the challenge of time keeping when factors such as the weather can affect their health. Being informed about these possible

career challenges prior to applying enabled participants to make informed decisions with consideration to the implications to their health (*'When things like weather can affect the condition it puts you off... it may pay well but I think my health is more important.'*).

Disclosure of Condition

Whether to disclose SCD to potential employers appeared to be a thought-provoking decision informed by prior experience. For some participant's disclosure was empowering as they could clarify how the job role may impact their health and their capabilities. Positive experiences of disclosing strengthened commitment and sense of security in the role (*'everyone was a team...I told him that I was ill before I got the job and he says you know what just do what you can and when you feel unwell just let me know and we can sort something out'*). Though, others felt employers just relied on their negative assumptions of SCD and it reduced their chances of getting the job and living a normal life. Perceiving the rejection of a role as an employer's loss served to protect participant's identities. Alternatively, non-disclosure despite the risk allowed participants to prove their ability and not miss an opportunity at an aspired career.

Theme: Experiences influencing relationship with the organisation

To manage the unpredictable and unremitting nature of SCD it seemed imperative for organisations and individual's principles to align to ensure security and commitment to the role.

Seeking support for work adjustment to manage health

Accessing support and adjustments within their role to improve their management of SCD was challenging for most participants. Discussions about the sacrifice of their health to live normally illustrated the fragility of SCD and the obstacles it created. Lack of control over access to support was found to create a sense of hopelessness (*'I've done everything they wanted me to do' and 'I don't know what else they really want me to do'*). Transparent communication with employers, being in a management position, having their own business and access to services such as *Access for Work* were beneficial in creating flexibility over activities and independence in managing their condition. Poor external support (e.g. GP, union) had detrimental impacts to participants physical and psychological wellbeing (*'I'd have the runs and want to vomit... I've had 33 blood transfusions in one visit that's how ill I was...thinking and overthinking... the mental state of you is bad'*).

Being an educator at work

As SCD is not widely advertised and discussed, individuals often need to educate others at their organisation. Some participants felt that informing employers explicitly about the intricacies of their condition was important as it created an environment conducive to relieve team work pressure (*'if I educate them about what sickle cell is and how it can actually affect you then my work life can be a lot better'*) and legally they could go to tribunal if wrongfully dismissed. Conflictual relationships developed following unreasonable requests and there was a perceived lack of choice in how to keep employers informed. There was hope that employers would recognise

participant's motivation to work and so resilience developed by reframing offensive comments as a lack of understanding.

Relationship with managers and colleagues

Participants commented on how their relationship with managers and colleagues influenced their experience at work. The unpredictable nature of SCD was often perceived by members of the wider team as unreliability and heightened their intolerance due to increased workload pressure (*'a lot of people thought I was putting it on which was really hurtful. I think it took me a long time to get over it all'*). Participants worked twice as hard when well to prove their value to the organisation despite recognising its detriment to their health. Harassment and negative regard of race led to feelings of powerlessness and decreased motivation to abide with organisations policies. Support from the organisation encouraged personal development and career progression. Support from external agencies (e.g. GP, union) encouraged employers to provide alternative activities during periods of recovery and ill-health.

Theme: Experience of being unemployed

Coercion to leave job

After a number of crises and health related sickness, employers were perceived to find a multitude of methods to fire or encourage the person to resign. The narratives portrayed an expectation for participants to cooperate with the organisations requests for information. Most participants referred to lawyers for guidance and reassurance which strengthened their self- concept. For some taking a case to tribunal however was considered a *waste of time* as it delayed the inevitable. Working within a challenging environment where employers coerced participant's out of their role had a detrimental impact to their physical, psychological and emotional wellbeing.

Life on benefits

Living on benefits is often construed negatively in the media and wider society. The narratives illustrated that receiving benefits often resulted in loss of self as job titles construct social perceptions (*'to have society sort of look at you as though you're a leech... [exhales] I don't feel great in myself as a person cos I think I've not really anything to offer I wonder what my father thinks...it's the hardest thing... your job defines the person that you are... if you're not working you're really looked down on'*). Receiving benefits was also considered as a period of reflection to reconstruct their identity as a worker.

Kind Regards,

Dominique Newsome

Trainee Clinical Psychologist

Appendix 12: Interview schedule

Initiate narration

The interview was initiated by the researcher saying to participants:

'This is a study about how you feel your experience of employment has potentially affected how you see yourself. I would like you to tell me a story about a point in your life when perhaps your relationship with work changed, and something changed about how you see yourself. Your story can begin as far back as you wish and recount in as much detail as you would like up until the present day.'

Prompts to encourage story- telling

- Can you recall anything else about what led up to that time?
- What else was happening at that time?
- What do you remember most about...?
- What happened next?

Questioning phase evidence

According to Jovchelovitch & Bauer (2000) the questioning phase is where the 'exmanent questions of the interviewer are translated into immanent questions using the language of the informant to complete the gaps in the study.'

Rules are:

- No why questions only questions concerning events (e.g. what happened before/after/then?)
- No direct questions about opinions, attitudes or causes. Allow rationalisations to occur spontaneously
- Ask only immanent questions (i.e. those which translate the researchers' knowledge and languages using only the words and expressions emerging from the interviewee's narration). So, questions refer both to events mentioned in the story and to topics of the research project. Translate exmanent questions (i.e. ones emerging from the researchers' background knowledge and interests as well as from the languages and vocabularies they use) into immanent questions.

To avoid a client of cross- examination, do not point to contradictions in the narrative

Appendix 13: Table of storylines

'This has been removed from the electronic copy'

Appendix 14: Letter of full ethical approval from Salomons Ethics Panel

‘This has been removed from the electronic copy’