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**RESIGNIFYING THE SICKLE CELL GENE: NARRATIVES OF GENETIC RISK, IMPAIRMENT AND REPAIR**

**Maria Berghs, MA, MA, PhD**

Research Fellow, Department of Health Sciences, Seebohm Rowntree Building, University of York, York YO10 5DD

Email: [maria.berghs@york.ac.uk](mailto:maria.berghs@york.ac.uk) (Corresponding author)

**Simon Dyson, BSc (Soc), MPhil, PhD, DSc**

Professor of Applied Sociology, Room 1.27 Hawthorn Building, De Montfort University

Leicester LE1 9BH

Email: [sdyson@dmu.ac.uk](mailto:sdyson@dmu.ac.uk)

**Karl Atkin, BA (Hons), DPhil**

Professor, Department of Health Sciences, Seebohm Rowntree Building, University of York, York YO10 5DD

Tel: 01904 321355 and [karl.atkin@york.ac.uk](mailto:karl.atkin@york.ac.uk)

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**Resignifying the Sickle Cell Gene: Narratives of Genetic Risk, Impairment and Repair**

**Abstract**

Connecting theoretical discussion with empirical qualitative work, this paper examines how sickle cell became a site of public health intervention in terms of ‘racialised’ risks. Historically, sickle cell became socio-politically allied to ideas of repair, in terms of the state improving the health of a neglected ethnic minority population. Yet, we elucidate how partial improvements in care and education arose alongside preventative public health screening efforts. Using qualitative research based in the United Kingdom, we show how a focus on collective efforts of repair can lie in tension with how services and individuals understand and negotiate antenatal screening. We illustrate how screening for sickle cell calls into question narrative identity, undoing paradigms in which ethnicity, disablement and genetic impairment become framed. Research participants noted that rather than ‘choices’, it is ‘risks’ and their negotiation that are a part of discourses of modernity and the new genetics. Furthermore, while biomedical paradigms are rationally and ethically (de)constructed by participants, this was never fully engaged with by professionals, contributing to overall perception of antenatal screening as disempowering and leading to disengagement.

**Keywords:** risk, ethnicity, disability, carrier, genetic and sickle cell

**Sickle Cell and Public Health**

Sickle cell disorder (SCD) is an inherited chronic illness, “associated with episodes of acute illness and progressive organ damage”, and is “one of the most common severe monogenic disorders worldwide” (Rees *et al.,* 2010: 2018). The disorder can be life-threatening but as SCD, “is an umbrella term that includes sickle cell anaemia, haemoglobin SC disease and sickle β-thalassaemia” (Atkin and Ahmad, 1998: 446), the symptoms can also vary in severity, adding to its complexity.

Carrying the sickle cell gene acted as protective mechanism against malaria and is found in areas where malaria either was or is endemic (Bunn, 2013). SCD primarily affects people of West African, African-Caribbean, Indian, Arabic, and Mediterranean origin. While previously a marginalised medical condition, migration and inter-marriage entails that SCD has become part of a global public health agenda (Dyson and Atkin, 2011; Piel *et al.,* 2014). In England, 1 out of every 2000 births is affected and 1 in 70 babies carry a gene relevant to SCD (NHS, 2012), making SCD one of the most common recessive disorders. Previous, non-comprehensive and geographically variable, ante-natal sickle cell screening was formalized in 2001 by the NHS Sickle Cell and Thalassaemia Screening Programme as part of general antenatal care in 2001. A linked neonatal programme (orientated towards early identification and treatment of those with the disease and not identification of carriers) was established by 2004. In 2013 this linked screening programme became part of Public Health England

Facilitating informed choice among those at risk of recessive disorders is a key policy objective for Public Health England. One of its aims is to provide *timely* antenatal sickle cell screening to all couples. If a mother is identified as a sickle cell carrier, with her permission, her partner *should (sic)* ideally be offered a blood test, thereby enabling the couple to make a decision on the future of the pregnancy. Yet, evidence indicates that fathers are tested in less than 9% of pregnancies (Dormandy *et al.,* 2010). Such findings threaten policy objectives and the ability of couples to make what are constructed as ‘informed choices’. This process is further compromised as policy sets the stage of where and how decisions should be made and frames normatively what is risky.

In this paper, linking theoretical discussion with empirical qualitative work, we examine how sickle cell becomes a site of public health intervention in terms of ‘racialised’ risks. Historically, SCD becomes socio-politically allied to ideas of repair, in terms of the state improving the health of a neglected ethnic minority population. Yet, partial improvements in care and education for those affected arose alongside preventative public health screening efforts. Using qualitative research, we show how a focus on collective efforts of repair can lie in tension with how services and individuals understand and negotiate antenatal screening. We illustrate how screening for SCD calls into question narrative identity (Ricoeur 1984), undoing paradigms in which ethnicity, disability and genetic impairment are framed. While biomedical paradigms were engaged with and ethically (de)constructed by participants, the latter’s discourses were never fully engaged with by professionals, contributing to overall perception of antenatal screening as disempowering and leading to disengagement. Before examining these paradigms, we elucidate how SCD becomes linked to repair and how narratives of identity (Ricoeur 1984) become implicated, in terms of setting the scene to understand antenatal sickle cell screening.

**Screening: Narratives of Repair and Risk?**

In the popular imagination, sickle cell is still commonly misconstrued as a ‘black’ disease (Carter and Dyson, 2011). Historically too, ‘ethnicity’ and ‘blood’ are associated with ‘consanguinity and racial kinship’ (Nelson, 2011: 116). In the United States (US), Tapper (1999) identifies several ‘scripts’ linked to SCD in terms of a history of suffering tied to slavery, exploitation of colonialism, racism and discrimination. Furthermore, screening becomes implicated in such scripts (Wailoo and Pemberton, 2006) within a “nexus of ‘race’, class, gender and the body” (Nelson, 2011: 145).

In the 1960s and 1970s, African-American protests framed access to health care, information, services and screening for SCD in terms of making visible the neglect of an invisible disease (Nelson, 2011). Community and voluntary services in England too, understood access to health care services and screening within a (bio) politics of repair of risk to the ‘black’ body (Clare, 2007). Thus, activism was also linked to a common genetic and ‘racial’ identity. In these early protests, parents’ and patients’ voices for better care in services, information and research on SCD occurred concomitantly with, as well as in opposition to, implementation of public health screening.

These early ‘scripts’ or people’s narratives for better services and screening are what Ricoeur (1999) terms the memory’s work in ‘telling otherwise’. They constitute the ‘collective memories’ that people use to make sense of the personal meaning of SCD. In the US, screening often went hand in hand with reified inequalities in services and society in general. The early unregulated screening had unintended bio-political consequences, in that information on ‘carrier’ status was used to discriminate (Nelson, 2011). The sickle cell gene acts as a sign which has to be mediated by other signs, such as for example ‘race’, in personal and historical contexts. The gene thus seemingly acts as ‘trace’ or ‘sign-effect’ in that it is a ‘mark’ that has been left of the past but is open to empirical and existential interpretations (Ricoeur, 1988).

According to Ricouer, narrative identity can be sameness (idem), as well as moral constancy throughout change (ipse). Ricoeur (1998: 90) explains, "Sameness is the permanence of a person's fingerprints, or genetic code," whilst, "the paradigm of the ipse identity is, for me, making a promise. I shall hold firm, even if I change; it is an identity that is willed, sustained, one that proclaims itself despite change." The promise, for Ricoeur, is an ethical act of responsibility that we have toward others. Furthermore, to develop Ricouer (1984), we would anticipate that people would use narratives to make sense of actions such as screening for risk of sickle cell trait. This means that we understand the act of screening by: 1) our retrospective preconceived understandings of SCD or what it denotes as sign or symbol, 2) plotting it against other actions in time, and 3) reconfiguring it in narrative form in terms of our life experiences and actions. Ricoeur describes being interested in, ‘limit-experiences’ or situations when “ipse identity is thrust back to confront its own interrogative form: Who am I?, without the response that could be provided by identity understood as sameness" (Ricoeur, 1998: 90). It is these experiences that we are interested in our study, as risk of sickle cell changes the embodied ‘sameness’ on which the ethical framing of identity is based.

Unlike Ricouer’s understanding of genetic code, Hacking (2006: 90) elucidates that we are now moving towards increasingly sophisticated understandings of genetic markers as ‘risk factors’ for illness, disability and (allegedly) to locate ethnicity. This has epistemological and ontological consequences, as well as ethical ramifications in that people critically question not only who they are but how they should live. It also calls into question the offer of screening as routine. Yet, in not treating ‘care’ as routine, the patient is typically viewed as ‘medically and socially’ difficult (Rouse, 2004). Health care professionals often strategically locate moral responsibility and blame for care-giving acts within the patient. This ascription of responsibility and blame happens today, for example, when health care professionals deride women ‘presenting late’ to the antenatal clinic or men ‘refusing’ to test for SCD. We wanted to investigate how people conceptually understood what genetic risk factors signify in screening, with what implications for understandings of ethnicity and disability? Similarly, how does risk of sickle cell become linked to ideas of agency and choice?

**The ‘Racialised’ Body, Disablement and Genetic Impairment?**

Social distrust in genetic medicine and questioning of concept of ‘risk’ is often greatest in groups that are impacted the most by genetic testing, such as ethnic minorities or disabled people (Schwartz, 2007). Consequently the new genetics, and in particular prenatal diagnosis and screening, have received considerable scrutiny (Parens and Asch,2000; Shakespeare, 2013). The ‘expressivist objection’, that prenatal diagnosis implicitly devalues disabled people, has been challenged by research, illustrating that the issues are more complex (i.e. Kelly, 2009; Boardman, 2014a,b). Shakespeare (2013: 115) has argued that disability rights advocates have two main concerns when thinking about prenatal diagnosis; eugenics on basis of impairment, and the possibility of discrimination. He discounts both. Yet, Boardman (2014a) elucidates that there has been a lack of empirical evidence to illustrate how experiences of a genetic condition influence reproductive decision-making. Likewise, we need to interrogate what is understood by ‘disability’, in terms of differentiating between various conditions and genetic tests (Broadman, 2014b), but also to understand how a genetic condition becomes ‘risky’ in antenatal care.

The definition of ‘disability’ as medical disorder has been contested in both medical sociology and disability studies (Scambler and Scambler, 2010; Thomas, 2012). In England, a social model of disability was defined against medicalisation that views disability as fault in the body that needs to be fixed or prevented (Oliver, 1983). Instead disability is understood as social oppression due to barriers, (dis)ableism and exclusion from social life, imposed on top of physical and/or mental impairment (Oliver and Barnes, 2012). In many ways, this could be another reading of a hermeneutics of suspicion (Ricoeur, 1998) or a reconceptualisation of risk. Yet, medical sociology has tended to ignore this social model by focusing on ‘chronic and disabling conditions’ noting these are illnesses (Scambler and Scambler, 2010). Theorists have questioned whether, within a Marxist/materialist perspective, impairments are also not also socially constructed (Abberley, 1987), personal (French, 1993), limiting (Crow, 1996) or reinforce a Cartesian dualism of the body implicit in biomedicine (Hughes and Paterson, 1997). Some of the strongest criticisms have come from feminism, critical ‘race’ theory, cultural studies, post-modernism and post-structuralism

- culminating in critical disability studies (CDS) (Corker and Shakespeare, 2002).

At the forefront of CDS, Corker (1998) argued against any dualism, insisting that both ‘disability’ and ‘impairment’ were socio-culturally constructed but that impairment led to social oppression. Thus, Meekosha and Shuttleworth (2009) argue the primary function of CDS is a critical interrogation of ‘disability’ and ‘impairment’ and how they become ‘embodied’ risks. Goodley (2014) elucidates that attention has to shift to unmask how ableism is constructed (i.e. in diagnostic categories predicated on able-bodied norms) to understand disablism.

In response, Thomas (2012) takes a critical realist position, arguing that it is important to understand the relationship between both risks of (dis)ableism as social and impairment as real. For her, ‘impairment effects’ are;

The direct and unavoidable impacts that ‘impairments’ (physical, sensory, intellectual, emotional) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course (Thomas, 2012: 211).

Ethically, what is problematic is not whether impairments are real or not but the relativism of all above positions in that no normative judgements are made (Vehmas and Watson, 2014). Yet, Vehmas and Watson (2014) do not apply their theoretical position to the practicalities of the new genetics. For example, if SCD is part of a government screening programme, one could argue that despite the apparent ethical relativism of individual choice, normative judgements about SCD requiring eugenic prevention have already been made. Our investigation thus centres on such a context, the ante-natal screening clinic, framed as offering ’informed choice’ to men from ethnic minority groups, who have typically otherwise been marginalised from the social entitlements to effect choices. Social histories of SCD attune them to critical narratives, and as we shall see, attempts to effect a restoration of meaning of SCD are confounded by an institutional setting which frustrates meaningful ethical communication.

**Methods**

This qualitative study was conducted from January 2012 to April 2014, in partnership with seven voluntary sector organisations for SCD. It took place across England in areas such as Birmingham, Manchester, Leeds, Leicester, Liverpool, London, Sandwell, and Sheffield. It received approval from the National Research Ethics Service.

The study conducted six focus groups with 50 young people, aged 18-35, from ethnic minority groups at possible risk of SCD, who did not have children and were in a relationship. We explored the extent men and women thought fathers should be involved in antenatal screening. We held separate discussions with men and women of African, African-Caribbean and mixed ethnic origins. We then conducted 24 in-depth semi-structured interviews with fathers to explore their experiences of ante-natal screening. A selective sampling strategy sought maximum diversity in terms of age, ethnicity, religion, socio-economic background, geographical dispersion and carrier statuses. Both focus groups and father interviews also included people with SCD, people who had partners with SCD or fathers of children with SCD. In order to locate the findings within the realities of service delivery we undertook 19 telephone interviews with professionals and two health commissioners involved in antenatal screening. Several voluntary sector community meetings and events were also attended and ethnographic notes made.

Interviews typically lasted an hour and were digitally recorded, transcribed, anonymised, and then analysed using *Atlas Ti*. This was conducted according to a constructivist grounded theory approach (Charmaz, 2005) which understands reality as socially created and relatively interpreted. A grounded-theory approach was used to ensure we engaged in constant comparative analysis and to allow us to bring a critical inquiry to our assumptions, definitions and theories (Charmaz, 2005). Analysis began using ‘open coding’ but focused on ‘line by line’ analysis. This was to ensure we did not get too immersed in our participants’ ‘worldviews’ or our own overarching themes too early, keeping interpretations open (Charmaz, 2006: 51).

Then we coded emergent themes according to hierarchy and thematically. We also paid attention to recurrent themes, silences and case studies through memos. We coded the transcripts individually, thematically and collectively. This analysis was presented and discussed at several points with two other members of the research team to challenge data analysis and aid theory development. We also presented findings to six community stakeholder groups to ensure analysis was kept open to their differing interpretations.

**Findings**

Our findings interrogate screening for sickle cell as experience calling into question moral constancy. We examine how people use narratives to make sense of actions such as screening for risk of sickle cell carrier status. We illustrate: 1) participants’ retrospective understandings of antenatal care and what it denotes as a symbol linked to disability, 2) the conceptual plotting of sickle cell screening against other narratives and actions in time to show how genetics becomes linked to ethnicity, and lastly, 3) reconfiguring the meaning of sickle cell within antenatal screening calling into question the links to impairment and destabilising concepts such as illness, disability and ethnicity. While it is presented as positive service, fathers learn to be suspicious of screening and attempt to reconfigure a meaning congruent within the social and ethical contexts of their lives.

*Preconfiguring antenatal choices, rights or risks?*

Fathers felt it was necessary to be conspicuous in undergoing routine testing, which was initially normatively framed and understood as a ‘good’ or ‘right’ thing to do (Dyson *et al.,* 2015). Antenatal screening was viewed in terms of necessary but routine public health surveillance of ‘risk’. Yet, young women, men and health care professionals noted moral ramifications for women linked to their age, health (i.e. diabetes, high blood pressure, genetic condition or carrier status), behaviour (i.e. drinking, smoking, drugs, ‘risky’ sex) and ethnicity (low or high risk).

Testing for risk was also clinically inscribed in health care discourses and visible technological practices, in terms of blood tests, scans, ‘clinical checks’ and screening tools, like the Family Origin Questionnaire that assessed family history and ethnicity. Professionals also framed screening in ways that presumed all family members have the same vested interests (familism) with screening presented as beneficial to the health of the mother *and unborn child*, although they stated the different tests were ultimately a *woman’s* choice. The normative framing and scientific technology involved meant that participants felt that antenatal screening should mitigate risks. Health care professionals were more nuanced:

*Well sometimes it’s not an exact science, and particularly with the Down’s Syndrome screening and things like that, you’re looking at the probability and the high risk, and within the congenital anomaly scan, there’s no scan one hundred percent positive. (…) But it’s just that, no screening is an exact science unfortunately, and you try to get as low a false positive and false negative as you can, but just because of the way it is, it’s not always possible.*

How well choices of tests and genetic probabilities were understood differed widely but all participants related that the ideal of engagement with antenatal screening was now of a ‘perfect’ baby (Buchbinder and Timmermans, 2011). It was the ‘risk’, ‘chance’, or ‘probability’ of a specific but abstract condition which had to be prevented. James a 27 year old father with SCD of African origin related:

***Q****: Did you understand what all the different tests were like, you know, you knew what CF was, you knew what Down’s Syndrome was, or did you have to read up about those different things?*

***James****: Actually, I don’t. Up to now, I just knew them as names.*

When asked about ‘disability’, participants recounted what they believed to be a connection to visibility of imperfection being screened for. For example, a young woman in an African-Caribbean focus group explained, “Obviously, you expect your child to be perfect, ten toes, ten fingers, and you know, two eyes, one nose, so it’s good to have that option there.”

Participants explained that if you accepted screening for Downs Syndrome or did not take up certain tests this was ethically perceived as an individual decision but also personal responsibility. The same young woman who explained that it was ‘good’ to have the choice of termination, also noted:

*Would you bring up a Down’s Syndrome, would you bring up a child with anything, Duchene, but I definitely would, cos at the end of the day, it’s a life I created so I would genuinely just bring up the child. But I think it’s a risk that I am taking for both me and my child, so I’d feel it for the both of us, to be honest.*

These ‘risks’ were affected by socio-economic background, partner, family and social support for a pregnancy, as well as experiential experiences with various conditions screened for, available finances and socio-cultural perception of the condition. The religious and socio-cultural acceptance of termination for a condition as disabling, and its early timing, were important considerations.Yet, peer supports, role-models, and judgements of decisions, for example as ‘selfish’, were also important moderators for young people and fathers. While termination for Downs was openly discussed by all participants and testing normalised, termination for a variable and invisible condition like SCD evoked more ambivalent attitudes. Applying the terminology of ‘disability’ to SCD was resisted by all participants unless necessitated by bureaucracy. A professional elucidated, “People with sickle cell don’t want to feel as though they’re less of a person and that label ‘disabled’ actually says that.”

Participants also struggled with negative ascriptions of SCD as ‘disease’ or ‘disorder’. Yet, participants who were not professionals could not explain what it implied outside of a genetic or social paradigm as this excerpt from a focus group with mixed heritage women illustrates:

***Q****: But why is it important?*

***F1:*** *Because if you don’t do it then your child could have sickle cell disease. You won’t know, you won’t be able to provide his monthly living…*

***Q****: Okay, why are there consequences of having a child with sickle cell disorder? Do you know?*

***F4:*** *That is just what I was about to ask? I know what sickle cell is but I do not know how it affects the child.”*

Health care professionals often related information about SCD in terms of genetic probability, ill health and ethnicity. They deemed Africans and young men most risky and least likely to test, subsuming individual risk within an alleged collective racial problem of masculinity. However, these participants often recounted socio-economic difficulties and fears linked to testing, like knowing people with SCD who were severely affected, stigmatised or had died. Men indicated perceptions of testing were influenced by relationship to partner, extended family, services, socio-cultural background, awareness and education on SCD. This also changed across the life-course, was dependent on how severely other children or relatives were affected and influenced by understandings and experiences of available healthcare, social support and research in a transnational context.

Furthermore, fathers noted that decisions on termination could be affected by ability of the family to ‘cope’. Samuel, (33, African), explained that before his son received treatment reducing the frequency of painful illness episodes, he would not want his worst enemy to go through his ‘suffering’. Other fathers, who felt children were managing, raised concerns about their second class status in services and lack of research for a cure. Additionally, James added that within services, “I rarely ever meet people that have adequate knowledge.” This also added to experiential experiences of uncertainty, alienated fathers from health services, creating the paradox whereby fathers and service providers mutually regarded one another as ‘risky’.

Young people also indicated that if they knew nothing, or nobody with SCD, they might consider termination. A focus group with African-Caribbean women generated the following exchange:

***F2:*** *But, I think, sickle cell’s another thing. I look at you and I, I think you’re normal, well you are normal, you know what I mean (laughter) I think it’s, that’s minor to me so I would keep my baby.*

***Q:*** *But you know her, she has sickle cell.*

***F2:*** *Yeah, and it’s not, she’s…*

***F1:*** *Yeah, it’s different…*

Counselling from the voluntary sector, Pentecostal churches and screening within educational contexts and before marriage, in places like Nigeria, meant some participants were aware of carrier status or had been tested before. These participants talked about ‘carrier’, ‘trait’ or more often than not their ‘haemoglobin status’ explicitly framed in biomedical discourses. They elucidated being encouraged to find out a partner’s status before relationships became serious, a concept they struggled with. For example, one young man in an African-Caribbean group asked, “I just want to know (…) is it unfair of me if I don’t tell my partners I’ve got the trait?”

Unable to express what the relational risks were, because they were so stigmatised, carrier status became framed within ideas about mechanical fault symbolically lying in the male blood and genes (Reed 2009). A young man of African-Caribbean origin, a carrier, referred to genetic impairment, “Like I say, I don’t really have a hundred percent secure gene, I have this genetic malfunction.” A health care professional explained this in terms of ‘disability’, “They will not be able to produce healthy children. So, that is the reason why none of their family will make them marry to that individual person.” Yet, few participants understood or were made aware of the real biological implications of carrier status, reproductive options (such as pre-implantation genetic diagnosis), let alone the latest technical developments that might have an influence on their decisions. Similarly, stigma became connected to SCD despite a changing aetiology of risk.

*Configuring a changing aetiology of risk*

Most participants believed SCD was a ‘black’ issue. In a focus group with men of African origin, a young man stated: “I thought it is only black people that got it.” George (35, African-Caribbean) made the link to racism, “…it wasn’t in the public eye because it only affects the black community.” David, (32, African), explained:

*There’s not much attention given to it. Because when we go to the sickle cell clinic, the majority of people you see are black, so what kind of voice would they have? Their voice wouldn’t be that loud.*

In a group with young women of mixed origin, a young woman explained how racism and neglect by the ethnic majority led to SCD’s insularity but also stigmatisation:

*It’s been heavily emphasised that this disease is attached to these ethnic minorities (…) So, like people who are not of colour undermine it or brush it off. I’m not, sort of thing. So, it’s not something that they would test for.*

Other participants pointed to the instability of ‘ethnicity’. The partner of one father said that while she looked ‘white’, she was of North African origin, but health care professionals never queried her about SCD. The voluntary sector was aware of the changing aetiology of risk and a professional explained:

*One in every four hundred or so white UK births has the sickle cell trait, so, and with mixed race relationships and a diverse population, we’re moving away from sickle cell being an almost, as it had been thought of, almost exclusively, you know, a ‘black disease’.*

A midwife located a lack of this understanding of future risks within both voluntary and health services:

*I must say we’ve done a lot in this country, it’s beyond a BME issue, I think it’s beyond that now because of mixed marriages, isn’t it? (…) My colleague who has got the poster that he used to teach the midwives, they are brothers, one is black, one is white and when we ask them, whom do you think is a carrier, most midwives will say the black one, whereas it’s the white one, you know. And we use that in our training. Do not presume that it’s a BME issue, and I think it’s more than that now.*

Yet, in the above extract, while SCD becomes a public health issue, it is still reified within categories of ‘race’, blood and invisible genetic transmission. In addition, dominant discourses discourage ‘at risk’ couples from marrying and encourage the ‘good father’ to get tested for the ‘health of his child’ (Dyson *et al.,* 2015). In this way, screening is not framed as ‘choice’ but an imperative. A specialist nurse elaborated:

*I think there is an issue about young men seeming demoralised or think that whereby if I agree to have a screening test that means that actually there’s something wrong with them.*

George clarified, “If (African-Caribbean people) are told that, “You’ve got this disease.” That is demoralizing.” Thus identification as a ‘carrier’ was making visible and locating genetic fault within categories of ethnicity, gender and personhood. Men also indicated that they did not want to be ‘bystanders’ to a pregnancy and expected involvement as fathers (Locock and Alexander, 2006) but were instrumentally treated as absolute biomedical risks. Thus, Mohammed, a 31 year old father of Arab origin, explained how he felt he needed to let his wife know his ‘status’ because, “I’m afraid I will be rejected if they discover that I’m a carrier.”

Other fathers conflated SCD and carrier status believing if they were carriers they had the disease and stated that they felt ‘fit’, ‘strong’ or had no ‘symptoms’. Kwame, a 46 year old father of African-origin who only found out he was a carrier with his second partner, elucidated:

*The bit I know about sickle cell is that they are prone to illness and sickness but not me. When it came out that I was a sickle cell carrier, I thought that’s strange for me. Then I was told it was a C.*

‘C’ refers to another gene, which in combination with the sickle gene, can be associated with a milder form of SCD. Further in the interview, Kwame engages in a hermeneutics of suspicion (Ricoeur, 1998), of research and knowledge of variants of SCD noting that he has C which he feels ‘is okay’. He explains that in low incidence areas it is he and his partner who are educating the predominantly ‘white’ nurses they deal with. He feels they, as ‘carriers’, are being ‘studied’.

Fathers did have experiences with stereotyping, neglect, disablism and racism regardless of professionals’ ethnicity. Fathers related needing to be hyper vigilant in terms of why prenatal diagnosis and termination were offered but Kwame takes his suspicions further. Similarly, Lewis, (27, African-Caribbean), became angry, questioning why he and his partner were treated like ‘guinea pigs’. He felt he was not, and is not, informed about risks and choices. He asks professionals for the evidence behind putting children with specific varieties of SCD on penicillin but the science is never shown to him. Iyabo, (38, African), suggests a hermeneutics of suspicion becomes necessary as the boundaries and language of SCD keep shifting and their questions about treatment of children with SCD based on limited research are not taken seriously. The narratives of Kwame, Lewis and Iyabo open up a suspicion in terms of the biomedical nature of SCD and what is actually known about it. In what follows, we examine how and why fathers reconfigure SCD.

*Self-Repair of Risk: Reconfiguring impairment and it’s a/effects?*

SCD is located within a system of stigmatized signs (being ‘black’), collective memory of racialized medicine and ‘black’ reproductive politics predisposing it to a hermeneutics of suspicion. But it does so in the specific context of being offered late modernity’s framing of healthcare as quasi-consumer informed reproductive choice. It is this disjuncture between the rationalist ‘informed reproductive choice’ and the historical racism that comprises the dialectic out of which fathers must then reconfigure their ethical stance in the world.

Young people, fathers and even some professionals questioned why and how SCD became a genetic impairment linked to ‘disease’ and what the link to its’ ‘effects’ were. Hence, several fathers mentioned wanting to know their blood type or group as ‘special’. For example, Isaac a (31, Caribbean) stated:

*I’ve nothing to hide so it wasn’t an issue, being tested in general, having a blood test. I think for me, I was pretty more excited about finding out what my blood group was**(…) I was just really intrigued to find out if I was a rare blood or a proper blood (…)*

Rare blood groups have lots of antibodies, beneficial for conditions requiring multiple transfusions and through this association Isaac reconstitutes his normality as a ‘proper’ carrier. This is a counter narrative to carrier-status-as-fault and SCD as a life-limiting condition**.**Isaac also links blood, ethnicity and SCD together, reinterpreting biomedical discourses:

*I’m sure you can trace your sickle cell back to an African or a historical place in time. I’ve heard this (…) certain strains or traits of either blood or genetics come from certain, especially in African Caribbean people, goes back to a different, certain parts in Africa.*

Participants also challenged assumptions altered genes denoted genetic *impairment*. Chika, (42 African) said:

*I heard something which I’m not too sure might be true or not, but I heard if you have the S in your blood type, you’re a little bit more resistant to malaria. So, it wasn’t a worry. If anything, I thought oh, you know, it’s better for me.*

Most participants did not have counselling about their carrier status or its implications, for example, of undergoing anaesthesia or donating blood. They also struggled to make sense of how genetic impairment was located in ever smaller bodily units like blood and genes and how this was diagnosed. Some participants questioned the very origins of how SCD was instantiated. Laboratory tests produce continuous data: what percentage of the haemoglobin in each red blood cell is of what type, but the information is interpreted by a consultant into categorical data (a genetic carrier or someone with SCD). Thomas, (38, African) asked:

*I have something wrong with my card. I don’t know the percentage, they say you have sickle cell trait forty something percent. I don’t know what forty per, something percent means? (…) because I wanted to know more about it, thirty-five percent I have and the forty-three percent my partner have?*

Participants also understood genetic impairment linked to a disorder as having limiting effects or symptoms. Mathew (20, Caribbean), whose partner was a carrier with possible symptoms, explained he did not have such symptoms and hence knew he was not carrier. Isaac questions the very ontological classification of ‘disease’ and carrier status:-

*They don’t have the disease. No, they’re not trait. Sorry, they both have the disease. Right, sorry, yeah, again this is what I mean about (laughs) that it’s the mind-set. They both have sickle cell disease SC carriers.”*

The future temporal uncertainty of risk and repair can become problematic. Participants who confused SCD with carrier status, asked about needed lifestyle changes or reproductive future of children. In this way they constructed both disability and impairment as intergenerational and not just individual. Lewis questioned if certain physiological effects were not linked to his carrier status:

*Cos at the point, it’s only when my son is born I realise, like I feel most then, even before I felt my joints and that hurting me, but I was just thinking I’m tired or I’m stressed or what-not. But it’s actually finding out from having the trait you can actually still get some of the symptoms from obviously sickle cell where as your joints hurt (…)*

Other participants went further than the physiological or psycho-emotional effects and questioned what was being silenced about social impact of genetic impairment and potential for discrimination. Isaac asks:

*I may have sickle cell traits. What is the knock-on effect for it? I don’t know, for clubs or groups and things like that? So, that’s when it first really came to light to me. I personally don’t think I’ve had any adverse effects being just a carrier.*

Ike, (42, African), noted how suspicion lead to disengagement, necessary to ensure moral repair:

*They said, “Because you need a lot of counselling now because we know that you can easily continue to multiply a full-blown one.” But this child is just a special child, for her to have survived pregnancy without being detected and being planned for? It’s, she’s so special. So, we just believe that, we, and I need to let you know that many Africans at times prefer not to go through the test.*

Several fathers who were carriers explained they too had issues with prenatal diagnosis. Due to the timing of this test late in a pregnancy, and small but real risk of miscarriage, decisions around uptake were agonising for parents. Thomas felt having a needle inserted (which he describes as getting an injection) to check the amniotic fluid of his partner was too risky:

*If you ask me today to choose again for that injection I’m going to say no, because I can’t see the difference. I mean later on, I was thinking that as soon as we, you know that the baby is sickle cell disease, you start the treatment, but they were saying to me, no, she need to give born (birth) like first, then after five days. And I said, “What’s the point? What was the point to expose someone’s life, as you know that if it’s happen there is no treatment already?”*

Iyabo states he feels that it was not really ‘choices’ that they were being pushed towards but making ‘decisions’ (Rapp 2000) about termination. He notes that while the genetic counselling might have been non-directive it was highly emotive because of the normative framing of testing as the morally and rationally right thing to do:

*We did take a decision to have the child and when someone comes and says, “Okay, we’re going to have to run a test, because there’s a like probability...” It sort of makes you scared again. And when I say, sort of, it’s like if you don’t have this test, ah, then you actually should and you’re actually walking in the dark.*

Later in the interview, he questions the focus on screening as linked to ‘cost-effectiveness’ and reducing the numbers of children born with SCD. Instead, he wonders if the ethical emphasis should not be on finding a cure. This was repeated by several fathers who reported professionals, such as midwives, who framed SCD in terms of disablement. Hence, they felt they were being counselled towards termination, often at late stages in pregnancy, instead of gaining balanced non-directive information.

All participants felt that screening opened up more uncertainties but the ways in which risks were being framed was crucial to acceptance or rejection. In a focus group with young men of African origin, one young man thus pointed to a diffusion of idea of genetic impairment and its connection to normality of disease:

*So, it’s just something you need to know for yourself. It’s just like any other, it’s a genetic trait, at the end of the day, every, all of us, one way or another, in our family, one of our family has a genetic disease.*

**Discussion**

In this study, we were interested in sickle cell screening as experience calling into question identity. We illustrated how this occurred in peoples’ narratives of antenatal care. Prefiguring their narratives, our participants stated they had no choice but to engage with discourses of risk as they are framed by antenatal care. Risk meant testing for multiple, barely understood conditions, calling into question ‘informed choice’. Engaging with ante-natal screening led fathers to reconfigure their identities by ‘displaying’ their moral worth as ‘good’ fathers and/or citizens. Yet, this engagement also called into question the very structure of identity, in that it called into question the foundations of agency.

Participants, like Kwame, critically questioned what they were at risk from, through narrative reconfiguration of sickle cell. Additionally, the boundaries of structuring concepts like ‘disease’ or ‘disorder’ linked to genetic impairment, which had been symbolically clear in antenatal care or enacted in past narratives of screening, were now shifting within a (bio) politics of surveillance and implicated (self) repair of risk. Participants struggled with the amount of genetic information, technology and detail they were expected to understand. Those with the ‘carrier status’ or who had children with SCD, such as Lewis, illustrated how SCD became relinked to discourses of invisible transmission, contagion or essentialised in an asymptomatic body due to the link to ethnicity. In this way, participants had to reformulate ideas of genetic carrier status as asymptomatically embodied, which they rejected, were suspicious of or completely subscribed to, showing how sameness (idem) or difference (ipse) in identity became flexible. Some participants, like Isaac and Chika, questioned where SCD was located genetically, reframed negative into positive understandings, and questioned if a cure or reframing could not make impairment effects biologically redundant, thereby undermining foundationalist conceptions of the body at the core of some work on paradigms of impairment.

The theoretical concept of ‘impairment effects’ (Thomas, 2012) also becomes inherently unstable because while asymptomatic, participants explained this could be due to lack of current knowledge and that the social and possible discriminatory ‘a/effects’ were yet to come in terms of a social model understanding of ‘disability’ or ableism. This becomes ethically crucial, as one of our participants, Jacob, illustrates by asking how he should now live especially with respect to familial (kin) responsibilities. Isaac questions whether the relational ‘knock-off effects’ were yet to come in terms of memberships of clubs and so on. Furthermore, ableism and (dis)ableism also became destabilised, not only physiologically (i.e. in scientifically determining the location of genetic ‘fault’, ‘false positives’ but how and why that becomes ‘symptomatic’ or is ‘diagnosed’), but also socio-politically in questioning the framing of screening, care and potential of cure as faith or hope.

While such questions were important to sustain ethical action and responsibility to others (Ricoeur, 1998), it had no place in the ‘routine’ of antenatal care, affecting perceptions of justice and equality. Health care professionals adopted institutional priorities, as well as professional ideologies, that viewed antenatal screening and ‘informed choice’ as a moral good. Yet, there was often no ethical reflection about the neoliberal context of such a ‘good’ nor if ‘choices’ were really being presented when they were framed as the ‘right’ thing to do. Participants questioned this status quo, disregarded it, or disengaged from services. So, Iyabo makes moral judgements on where the norm linked to impairment should be (Vehmas and Watson, 2014) and questions the supposed ethical relativism as individual and personal.

In this way, ‘scripts’ linked to retrospective collective understandings of SCD become ethically relevant to participant’s narratives of suspicion of professionals’ ascription of collective and individual ‘risks’, challenging Shakespeare’s (2013) arguments that fears over eugenics are to be discounted. These discourses also informed present day analyses on how to think about what ‘impairment’ is and why concepts are ethically being ‘unmade’, such as for example, Chika questioning genetic *impairment*. We argue the theoretical disconnect of current paradigms of disability is because the nature of (bio) medicine has changed, in keeping with new ideas on genomics and where pathology is situated as more sophisticated but also diffuse, affecting everyone (Hacking, 2006; Vailly, 2008), foretelling a new genetic (dis)ableism.

Screening was typically viewed within matrix of prevention, governmentality and consumer demand of choice, a matrix that prevailed over either duty of care for people or finding a cure. The expressivist objection (Broadman, 2014a,b) and experiential experiences were also blurring because they were affected by structural, institutional, relational and individual understandings of SCD and in screening could not always be distinguished from the (bio)medical or genetic. Yet, the experiential ‘reality’ of SCD, carrier status, care and research were interrogated most extensively by participants who were carriers, had SCD or had children with SCD.

Participants’ engagement or lack of engagement with screening often stemmed from the disjunction between ipse, or moral demands of personhood, and idem understandings of genetic information. While screening presumes an inherent rationality of rejection of ‘risk’ of genetic impairment, participants elucidated hierarchies of choices within socio-political and scientific understandings they had identified. This was related to making an informed but relational ethical choice. Engagement with screening did not mean you accepted all the given choices, recognised (bio) medical understandings of risk of SCD, nor did it mean that children with SCD are not born.

**Conclusion**

Suspicion of risk and repair of hope are constantly deployed and refashioned in understanding the uncertainties of antenatal screening, carrier status and having a child with SCD. This is because the paradigms in which people understand foundational concepts such as ethnicity, disability and genetic impairment are changing. Participants understood their participation in this research as a call to moral action for greater awareness, better treatment and research on SCD. Testing for sickle cell carriers in antenatal care could be empowering, but the way in which it was framed within policy and practice was disempowering and potentially disabling and racist. Social histories of sickle cell, including its ongoing framing as a ‘black’ disease, meant that fathers treated the offer of antenatal sickle cell screening as an implied social good with suspicion. Institutional priorities, professional ideologies and wider political framings of screening as connoting prevention and/or reduced costs all distorted the speech encounter with the screening professional. They were then left, as Samuel added at the end of his interview, with the sense that while testing was ‘good’, it was more important to ‘be aware’ of what antenatal screening was really about and ‘ask questions’ in order to ensure moral constancy and orientate oneself ethically in life.

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