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Narrative as Re-Fusion: Making Sense and Value from Sickle Cell and Thalassaemia Trait

Abstract

The moral turn within sociology suggests we need to be attentive to values and have a rapprochement with philosophy. The study of illness narratives is one area of sociology that has consistently addressed itself to moral domains, but has tended to focus on stories of living with genetic or chronic illness per se rather than liminal states such as genetic traits. This paper takes the case of genetic carriers within racialized minority groups, namely those with sickle cell or thalassaemia trait, and takes seriously the notion that their narratives are *ethical practices*. In line with the work of Paul Ricoeur, such storied practices are found to link embodiment, social relationships with significant others, and wider socio-cultural and socio-political relations. At the same time, such practices are about embodying values. These narratives may be considered as practices that *re-fuse* what genetic counselling has *de-fused*, in order to make sense of a life in its entirety and to strive ethically and collectively towards preferred social realities.

Keywords: ethnic minorities, genetics, narrative, sickle cell, thalassaemia

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Narrative as Re-Fusion: Making Sense and Value from Sickle Cell or Thalassaemia Trait

Introduction

The 'moral' turn in sociology has led to a (re-)consideration of the place of values and normativity in social life (Sayer, 2005; Chernilo, 2014; Skeggs, 2014). This has been accompanied by calls for a rapprochement between sociology and philosophy, with sociology caught between awareness that our increasing capacity to analyse human fallibility is precisely what undermines our trust that we can intervene for the better, and standpoint normativities that presuppose what we actually need to explore (Chernilo, 2014). Thus we have posed for ourselves what the philosopher Marcel (1951) suggests are technical moral dilemmas, and have stripped the mysterious (how will people remain true to themselves and ethically accountable to others) from the understanding of our lives. For instance, the sociologist Rothman (1993) proposes the more we know about genetic carrier states in pregnancy, the more we are disenchanted about the philosophical mystery of a new human life. In this paper we consider the analysis of illness narratives as practices (Frank, 1995), and reinvigorate analysis by reference back to a key philosopher, Paul Ricoeur. A number of sociologists have examined narratives as practice, focussing on the body (Kelly and Field, 1996); on the others to whom the narratives are directed (Bury, 2001); or as resisting the dominant

symbolic order (McLaughlin, 2015), all the while emphasizing the moral (Bury, 2001) or the ethical (Frank, 1995) basis of that practice.

What has perhaps not been sufficiently considered is how narrative practice depends on the *integration* of these different elements, with concomitant implications for embodiment, ethics and politics. A philosopher capable of supporting an analysis attentive to values is Paul Ricoeur. Brockmeier and Carbaugh (2001) provide an overview of the development/trajectories of narrative within various disciplines, which encompasses narrative as linked inwards to identity and outwards to culture and society. The salience of Ricoeur to our analysis is because, across the corpus of his life's work, he develops ideas that show how personal meaning, situated ethics, resistance to domination/misrecognition, recognition of history and political futures all comprise and flow from his notion of narrative identity. Ricoeur integrates this range of elements at the philosophical level, just as we shall see that our respondents do with their narrative practice. In this paper we note the integrative dynamic of Ricoeur's philosophy, but refer also to the cultural sociologist Jeffery Alexander to understand why fusion of elements is important in narrative. We then broach our empirical examples, taken from a qualitative study of people identified as having sickle cell or thalassaemia trait, and how these genetic carrier states are communicated to people in biomedical discourse. The liminal quality of genetic carrier states poses a particular challenge to narrative identity, distinct from chronic illness. This is because *being* a sickle cell/thalassaemia

genetic carrier is also referred to as *having* sickle cell/thalassaemia trait. It is thus more than genetic risk, since having a trait entails real morphological changes in the body, and it is unclear whether or not this constitutes a diagnosis, and whether or not accompanying symptoms are sanctioned by the medical profession as legitimated sickness. In this paper we consider in detail two examples of people dealing with liminal genetic traits, before suggesting some conditions of, and implications of, recognising narrative practices.

Ricoeur and Narrative

Ricoeur was concerned with texts, but includes in this conception oral testimonies, of which illness narratives may be considered one variant. For Ricoeur, narratives imitate life, and we may learn much about life through narratives. Narrative is the only model that integrates two forms of time: time as succession-of-events and biographical viewpoints on time. This biographical viewpoint presages a particular conception of identity, consisting of *idem* (sameness, including, Ricoeur (1998: 90) states, our genetic code) and *ipse* (ethical self-constancy, being true-to-oneself over time) the latter comprising one's narrative identity (Ricoeur, 1998). This is how, for Ricoeur, narrative links to ethics: through narrative identity a person strives to be relied upon, to be counted on for their moral self-constancy. But being counted on makes one accountable to others, and so being true to oneself in the face of changing circumstances is a question of ethics, of placing oneself at the disposal of others.

Drawing on the notion that, employing the image of a fold in a sheet of paper, a body can simultaneously act and be acted upon (Merleau-Ponty, 1969[1964]), Ricoeur builds upon the notion that humans are embodied beings: *my body* presupposes that we simultaneously *are* a body and *have* a body (Ricoeur, 1992). However, this means that the nature of our link between body and identity is paradoxical: we have to attest that our embodiment is congruent with our private identity (Kelly and Field, 1996). Furthermore for Ricoeur ‘One becomes who one is through relations with the Other, whether in the instance of one’s own body or another’s’ (Atkins, 2005: §6). This means that we are mutually vulnerable and that our fate is intimately tied up with that of others, be they family, friends or neighbours. Moreover, self-esteem means being able to attest to oneself as being the worthy subject of a good life, and Ricoeur presages Frank (1995) in seeing narratives as ethical practices, displaying what we take to be right and wrong. Ricoeur (1992: 172) considers the ethical intention as ‘aiming at the “good life”, with and for others in just institutions’. Finally, justice depends on empathy in social relationships, on imputation of feelings to one another (Ricoeur, 1992), but also on remembering injustices of societal relations at the level of peoples and nations, (Ricoeur, 1996), on weaving personal with historical narratives (Ricoeur, 1988).

The Context of Genetic Information

The research sought to understand how people made sense of the information that they were carriers of a gene clinically relevant to the chronic illnesses sickle cell disorder (SCD) or beta-thalassaemia major (thalassaemia). Such people are described by professionals as *being* sickle cell or thalassaemia carriers or as *having* sickle cell/thalassaemia trait. Biomedicine frames such genetic information in three respects. First, at the level of the body, people with sickle cell/thalassaemia trait are labelled 'healthy carriers.' (Kai et al, 2009: 1). Having a trait obscures the division between health and disease, challenges processes by which people make sense of their bodies, and draws people previously considered 'well' into the sphere of medical interventions. A 'diagnosis' of 'healthy carrier' is arguably oxymoronic, with potential for confusion, and for undermining one's sense of identity. Evidence suggests difficulties of living with the indeterminacy of non-diagnosis (Nettleton, 2006), creating situations where lacking a coherent story causes distress (Clark and Mishler, 1992). As we shall see, narrative practice may be seen as a response to such bodily uncertainties.

Second, genetic information is presented as a social good, namely 'informed reproductive choice', and indeed some participants and NGOs subscribed to this grand narrative of 'knowledge is power', 'choice is good.' However, in screening policy, having a trait is reduced to being relevant *only* to reproductive decision-making. Genetic inheritance charts, showing the one-in-four chance in each pregnancy of a carrier couple having a child with the chronic illness, represent knowledge

that is technical, abstract, and de-contextualised from family lives. Such genetic diagrams presuppose heteronormative forms of family (Oikkonen, 2009) and medicalize kinship (Finkler et al, 2003). The presentation of genetic information predisposes to conversational turn-taking through closed questioning and emotional directiveness (Farrell and Christopher, 2013). All of this concentrates interpretive authority in elite hands (Alexander, 2006: 44). Against this, efforts by individuals to tell a story attempts to make sense of technical (genetic) facts (Clark and Mischler, 1992), and community stories (rumours) constitute resistance to medical power (Dingwall, 2001).

A third framing entails the racialization of sickle cell as reductively associated with particular ethnic groups (Carter and Dyson, 2011) and of thalassaemia with allegedly 'cultural' practices such as cousin marriages (Ahmad et al, 2000). This then links the traits to group identities, and, in this respect, narratives may be used to assert value in their lives, against external oppressive power (McLaughlin, 2015). Thus identification of genetic carriers re-asserts grand biomedical narratives at three levels, the body, social relationships with significant others, and social relations of group membership.

Methods

The research aimed to understand how people made sense of having sickle cell/thalassaemia trait. Following ethical approval from a university committee, the sample was generated with seven sickle cell/thalassaemia non-governmental organisations (NGOs), and, combined with snowball sampling, recruited 57 genetic carriers from four different areas. The sample comprised 22 female and 10 male thalassaemia carriers and 11 female and 14 male sickle cell carriers, aged variously between 17 and 70 (see Table 1). The theoretical and diverse nature of the sample is crucial, maximizing diversity in terms of age, gender, ethnicity, and the point in the life-course at which respondents came to know their carrier status. This ensured representation of carriers from diverse ethnic groups as a counterweight to racializing discourses that locate carrier status in one ethnic group (so, for example, Carol, of mixed White/Caribbean heritage, had thalassaemia trait, and not sickle cell, as was serially, and incorrectly, assumed by health professionals). It also ensured religious communities were not homogenised, so that the inclusion of (practising and non-practising) Indian, Turkish, and African Muslims meant the thalassaemia experience was not reduced to that of British Pakistani Muslims. On the other hand, the reason our two case studies emerge is that, being a Black Caribbean carrier of sickle cell and a British Pakistani Muslim carrier of thalassaemia respectively, they each have canonical community struggles to which they can connect their personal narratives.

[Table 1 here]

The NGOs were given recruitment fees and the participants paid a small fee plus travel expenses. Interviews invited respondents to consider sickle cell or thalassaemia trait, as appropriate, both in terms of temporality (when they found they were carriers) and in terms of biographical contexts over the life course that framed their dispositions. In this sense the nature of the co-production of accounts prefigured responses based on narrative identity. Interviews, of between one and two hours, were conducted by Sangeeta Chattoo (Chattoo, 2015) in English (51) or Urdu/Punjabi (6), and were subsequently transcribed and translated by an experienced multi-lingual researcher. Interviews were transcribed in full, except one where permission was not granted to audio record and hand-written notes were taken.

For the purposes of our analysis Ricoeur is helpful in providing insight into the broader meaning of narrowly defined medical interventions. The analysis presented is adaptive (Layder, 1998), only latterly drawing insights from comparing data to Ricoeur's ideas, and initially based simply on noting that participants made sense of sickle cell/thalassaemia trait in three ways. First, some reported physical effects of the trait, in opposition to received professional wisdom. Secondly, they made sense of being a genetic carrier in relation to significant others. Thirdly, they made connections to socio-cultural tropes, some of which are associated with the racialization of particular groups in the UK. In presenting our analysis we highlight two cases where respondents

have most compellingly integrated these three aspects. What makes it compelling is that narratives must be a stories which “violate canonical expectancy but do so in a way that is culturally intelligible” (Bruner, 2001: 30).

Embodiment, Social Relationships and Social Relations

The medical profession struggles with a conceptual ambiguity, naming sickle cell/thalassaemia trait as diagnoses, yet describing those with trait as ‘healthy carriers’ (Kai et al, 2009: 1). In the context of screening policies, people are trying to make sense of what, from their viewpoint, bears all the hallmarks of a diagnosis. It is therefore not surprising that most interviewees felt that a trait could, at least potentially, be associated with physical symptoms. Those with sickle cell trait referred to pains, especially in the context of cold, wet conditions or of exertion, precisely the types of symptoms and triggers that are associated with people living with the chronic illness, sickle cell disease (SCD). Health professionals emphasize the benign nature of being a sickle cell carrier and distinguish strongly between *being a sickle cell carrier* and *having SCD* (see Carter and Dyson, 2015). Those with thalassaemia trait reported anaemia, not usually deemed clinically significant, though family doctors were reported to mistake this for iron deficiency anaemia, prescribing ineffective iron supplements, while inducing other unwanted symptoms such as

diarrhoea. Thus there was a sense that it was important to 'own' your 'condition' (Vahini: 'It's you and you should know about what's going on in your body'). To be reconciled to your physical trait might mean that it does not interfere with other ways in which one is happy to attest to one's embodiment (Waheed: 'I'm healthy as a normal person, I can play sport, I can run, everything'), or alternatively it could be that carrying the trait accounts for unwanted bodily experiences that would otherwise be problematic to reconcile (Dalton: 'whereas if I didn't have the trait and I was always getting ill and I was always tired, then I don't know what I would put it down to').

In a second set of linkages, people connected their genetic status to their biographies and kin relations. For Ricoeur (1992) key questions concern who am I, and how should I be in the world? In linking sickle cell/thalassaemia trait to significant others, it might be argued that people are attempting to reconcile selfhood with their public identity (Kelly and Field, 1996). For some the trait indexes a broader responsibility to kin (Mamokoh: 'Having the trait means nothing to me, having the trait means for my son, I need to educate my son') though not necessarily a *genetic* responsibility (Hallowell, 1999), more a responsibility for wisdom across the generations (Mary: 'if you don't know anything, you can't tell anybody anything really. Because children like asking a lot of questions and if (as a grandmother) you don't have the answers, well it's not good (laughs)'). Ethnic origins were not always coterminous with the participant's sense of their family identity. Carol viewed her trait as the trigger to find out that the white father on her birth certificate was

not her biological father, but her search for said biological father, putting posters up in the local black neighbourhood, was 'seeking her history rather than a family connection'. A linkage was made the other way by Andrea, who felt closer to her aunties because they shared a thalassaemia gene: 'I don't really look like my aunties at all, [but] I feel like I have got some kind of connection (laughs)'. Both examples suggest that domains of importance of being a carrier are far wider than the narrow policy focus on reproductive risk.

People make sense of who they are in relation to others, but also to wider discursive practices, including racist discourses. Thus distress was evident where the professional discourse on consanguineous marriages and thalassaemia risk undermined their social relationships. If they were told that marrying cousins 'caused' thalassaemia (Tariq, Basheera), then why did some families with cousin marriages have children with thalassaemia but others did not (Madan)? And why did families without cousin marriages, or even white families, have children with thalassaemia major? (Habiba). Such dissonance may lead to broader questions about medical authority and competence (Ahmad et al, 2000).

For Ricoeur (1992) otherness includes institutional forms of association, and collective justice means remembering societal level injustices. The majority of our respondents also linked their trait to broader socio-historical issues. John states: 'all this slavery (...) anything could have

happened in them days (...) they could have had soldiers and high ranking people and they needed blood so they took the black person's blood out, pumped it out of them, give it to them' . Medved and Brockmeier (2008) refer to memory appropriation as one (individualist) technique to maintain a coherent sense of narrative identity. By contrast here our research participant appropriates from the canonical *collective* memory of slavery of British Black Caribbean people, in order to buttress her sense of her vigilant narrative identity, resilient to suffering and injustice. Other collective injustices, abuses of medical experimentation, or state-sponsored eugenics, were evoked by other respondents. The sister of Winston believed sickle cell was engineered by the Americans and taken to Africa, and that President Obama had apologized for these experiments. For Giannis and Alex, the Cypriot government's emphasis on thalassaemia prevention (through prenatal diagnosis and selective termination) is contested owing to their dislike of state intervention in family life (Giannis: 'why should it be in the hands of someone else whether you live your life with them (a carrier partner) just because something that's going to affect you more than it would the country').

So far we have seen that people with sickle cell/thalassaemia trait made sense of their carrier status by testifying to the relative unity of bodily symptoms to their self; through weaving the trait into their account of social relationships with significant others, and through connecting their trait to wider social-cultural narratives, narratives that implicitly were about communal resistance to

oppressive power. But theirs is one life lived. What the accounts have in common is that sense-making involves weaving connections of body and identity, of self and others, of groups and history, striving for coherence in the practice of their lives. We next move on to consider what has been separated out, how, and by whom, and what might explain the importance of reconnecting the disparate elements.

Narratives as Re-Fusion

Alexander's argument (2006) in relation to ritual and performance is instructive here. Ritual entails the fusion of material and cultural, whereas in societies based on complex divisions of labour such elements are often disentangled, that is to say *de-fused*. Genetic risk diagrams would, in this analysis, comprise 'texts composed by specialists for segmented sub-groups in complex and contentious social orders' (Alexander, 2006: 38). This de-fusion is associated with confusion when receiving genetic counselling: '(Genetic counsellor) was explaining positive/negative and positive/positive and negative/positive and all these things which were quite confusing at the time, obviously quite easy for her to understand' (Huri). Health policy segments groups by age (state-sponsored information on the trait focusses almost exclusively on risks at reproductive age) and ethnic groups (for example, the association of thalassaemia with Mediterranean/South Asian ancestry). This may lead to the recipient of medical information outside of these categories

considering it as irrelevant. So for example, Anne's thalassaemia trait was not relevant to the stage of her life-course (teenager) and was apprehended as an inconsequential marker of Greek Cypriot identity. Within Alexander's framework, informed reproductive choice, the manifest aim of screening in a liberal capitalist democracy, would be seen as instantiating '...individual choices that respond to the sanctions and rewards of social powers or segmented social groups' (Alexander, 2006: 40), and when during pregnancy Anne discovers, contrary to initial information given, that her partner is also a thalassaemia carrier, the extreme anxieties provoked felt like a moral test of their relationship and her moral credibility, in addition to representing a decision based on family experience and collective pressure within the Greek community that one does not raise children with thalassaemia. In seeking control through informed reproductive choice, genetic scripts (written foreground texts) are separate from background collective representations (such as the slavery example, below, page 15). In contrast to static genetic diagrams, people's experiences are highly sensitive to time and place. The genetic risk scripts are handed down, solicited or not, but must be made sense of in the context of changing personal and community lives. For Rosa and Duman, thalassaemia trait is sensitive to both time and place: for example, to their second generation transnational ethnic identity. The puzzling persistence of Duman's anaemia, despite parental insistence on a diet rich in fruit and vegetables, is shown by hospital tests to be anaemia related to his thalassaemia trait. The thalassaemia trait is reconciled in his embodied self, ('it's just part of me that I accept (...) you have paleness, or you feel like, I'm feeling

a bit lower on energy levels, it's just part of me') but also in his family relationships across generations ('with our young children we constantly instil eat your vegetables, eat your vegetables up'). Later in the life-course, food is also woven into the narrative at the broader level of economic relations (in the form of a food business) and to wider community relations in the form of fund-raising support for a thalassaemia charity (historically strongly associated with Mediterranean communities). The fact that the different levels of the narrative are fused together suggests the extent to which the couple are happy to attest to their embodiment, their social relationships and their place in the wider world. The success of such narrative performances lies in increasingly re-fusing disentangled elements (Alexander, 2006).

To apply Alexander's argument to our analysis, narratives have strength to the extent that they *re-fuse* the disparate elements, *re-fuse* the material body with social relationships of significant others, and with wider socio-cultural or socio-political concerns. Re-fusion, therefore, exists in relation to this de-fusion, while at the same time represents a different interpretation, independent of the original intention of the technical genetic intervention. Since this re-fusion runs counter to the de-fused elements presented by health professionals, it may be misrecognized as *re-fusal*, an averring of professional advice based on (professionally imputed) ignorance, wilfulness or denial of genetic risk. In exploring this further, we opt to outline two case studies to

illustrate how people strive to re-fuse body, social relationships and socio-historical relations in constructing affective life scripts.

Case 1: Hypervigilance

Linda is a Black Caribbean sickle cell carrier. Her story links a reluctant acceptance of the materiality of her sickle cell trait, which she asserts has an effect on her health, with the health of many other carriers she is in contact with on social media. For her the trait is associated with tiredness, stress and pain.

Nobody told me before with sickle cell trait that you've got to hydrate a lot. I've always been anaemic as well, which is probably not linked to sickle cell trait, but I think combined, that's how I have issues and problems with it. (...) when they make statement like 'there are no problem', 'there are no complications with sickle cell trait', they should be careful, cos it could be misleading. If there is something else which combined together, they can have an explosive effect, you know, those misleading literature needs to come off the public domain.

The denial of sickle cell trait symptoms in most public health advice leads her to believe that she must be watchful of doctors who may deny the symptoms whilst also gate-keeping access to tests when these are orientated to illuminating symptoms as opposed to reproductive risks.

The doctor's attitude as well (...) he wanted to suggest that the pain was all psychosomatic, and even the muscular pains I started getting (...) I find that they were more triggered if I was stressed, cold, or there was something else that brought it on, stress, cold and I think certain foods.

(...)

(Doctor) said to me 'What difference will knowing make?' (Interviewer laughs) because it still won't change my symptoms, that's what he said. But at least it would be education and I wouldn't have to keep having to feel like a freak when I'm explaining to people why I need air, (...) why I need some rest (...) cos sometimes people look at you and it's like they think you're just anti-social, yeah.

In common with accounts of sickle cell in Senegal (Fulwilley, 2011) her reports of pain associated with sickle cell trait provide her with an empathetic link to SCD pain. Her trait is made sense of through her link to a relative with the chronic illness itself: 'my uncle's wife had the full blown (i.e.

SCD), she died on an aeroplane a couple of years ago.’ The medical profession can mislead the public if they claim sickle cell trait is asymptomatic and her doctor disbelieves her when she attributes her pain symptoms to the interaction of sickle cell trait with other factors.

The issue of the medical profession and sickle cell symptoms is linked to wider social relations through the expressed idea that GPs may not provide carrier tests upon request (despite this being a mainstay of public health advice). More generally, minority ethnic groups do not get the best health services.

I’m going to get them both tested again, because the GPs fold their arms and they, they think, oh right, it’s just, or they do that because of the NHS cuts and cos there’s some really terrible things happening now with the GPs and not wanting to spend on, on even the simplest, smallest things.

Hers is a narrative of hypervigilance. Not only must she keep an eye on doctors who deny the (for her) real symptoms of sickle cell trait, but she is wary of threats from significant others. In retrospect she surmises that her first partner deceived her by hiding his sickle cell trait and that symptoms associated with her sickle cell trait put off a second prospective partner but, fortuitously, also protected her from exploitation.

He married me for a passport, so he would (laughs), he would you know be deceitful, and yeah that was the second. And the younger two, their dad said he didn't have it. But yeah, I've been really trusting, that's awful (laughs), oh God.

(...)

(Knowing I have sickle cell trait) probably keeps me from a wrong relationship as well (laughs) cos I know I'm, when I was really ill, you know, I was dating someone and I think, I think that that sort of scared him when I was ill and so maybe it's a protective thing in more ways than one, and he wasn't right for me. So it's good. If, if something like that scares someone away, it's also good I guess.

At the broadest level of socio-historical relations the trait contributes powerfully to her overall narrative, explaining the preponderance of sickle cell trait in the Caribbean as an artefact of those captured in Africa and transported across the Atlantic as part of the chattel slave trade.

(I got sickle cell trait) from my mum's side (...) it made a lot of sense to me, when I thought about the slave history, the slave trade, I thought I bet you that's why there's so much of a concentration of people with the trait down in the Caribbean. Maybe those were the slaves who were easiest to capture, you know they couldn't outrun the

others, they got tired quicker. They were probably the easiest ones to capture, the ones with the trait, and even the dying at sea, you know, the hypoxia rate would have been phenomenal in the slave ships.

Her belief that she suffers sickle cell-related pains, in contradistinction to received medical wisdom, is buttressed by the experiences of significant others: her own mother and others on social media who claim likewise. Such experience provides a bridge to empathise with her aunt, deceased from SCD, but also to be hypervigilant, lest she is victim to exploitation in romantic relationships. Such hypervigilance is also applied to social relations: wariness of doctors who might deny African-Caribbeans a fair share of health services and of the historical legacy of slavery in relation to the challenge of sickle cell for black people. A narrative of hypervigilance is the basis of re-fusing abstract genetic trait with her body and family ('now I could link it', she reflects, when her mother shares experiences of cold season arthritis); with social relationships with potential partners and with wider societal racisms in health services or at the level of the socio-political history of slavery. Hypervigilance might also be oriented to resisting unwanted or unhelpful medical services (prenatal diagnosis and bone marrow transplantation) as in our next case, which demonstrates striving for moral self-constancy, not only against medical procedures but against moral interpretations of illness as a punishment from God, made by community members, and caricatures of religion and culture made by wider society.

Case 2: The Ethical Intention

Naeema, a British-born Pakistani Muslim thalassaemia carrier, reports feeling tired and lacking energy, being intolerant of foods she previously ate, and suffering diarrhoea when intolerant of iron medication. She accepts her thalassaemia trait in that she attributes some symptoms to it, and would willingly show the card showing her genetic status to health professionals.

In terms of social relationships, she rejects those within her community who attribute chronic illness to divine punishment (in Urdu: 'You are being punished for something you did wrong. This is not a nice thing to say, I really hate this type of remark') but equally rejects health professionals who attribute thalassaemia to consanguineous marriage, reasoning that others married to cousins have no children with thalassaemia, but some not married to cousins *do* have children with thalassaemia (see Ahmad et al, 2000). The consanguineous marriage of her parents can only be understood in the context of her father supporting her mother, whose first husband and brother died, leaving her alone.

(Mum) was married to someone else and he passed away and then they got married because she was only one child. She had one brother (who died) (...) and my mum was

like alone, the only child, and then my Dad kind of took pity or whatever he called it but he said that's why I wanted to marry your mum, just to look after her.

Her account is important because it frames consanguinity as a practical, contextual and relational activity (implicitly challenging its reductive hypostatization as 'cultural') and because, in terms of hermeneutics (Ricoeur, 1967), what she says has a symbolic reading (consanguineous re-marriage as moral repair of the social fabric) as well as a semantic one. The challenge of her own extensive caring for her own children with thalassaemia, her loss of a daughter to an early death, and the fostering of several children from within the extended family - in short the weight of the world - is encapsulated in her account of the collapse of the floor at a family funeral, with the fall causing her to miscarry.

Three (children) died within the space of five years...when he died we had a funeral at our old house, (where) our parents lived. It used to be a corner shop, you know commonly known 'Asians with a corner shop!' And the floor gave way and we all collapsed into the cellar (...) and I was pregnant, but I didn't know I was pregnant (...) and my foster children had just come into my life.

(...)

(Foster children's') mum was ill and (their) dad was very neglectful (...) because I had that much stress and because the floor collapsed and we fell through into the cellar (...) then they told me you have miscarried.

Nonetheless she learns how to be a mother of a thalassaemic child through praxis. Her husband defies stereotyping of Muslim men by encouraging her college studies, being self-reliant in housework, and her father by being both restrictive in some and progressive in other ways (hating forced marriages).

(Husband) had to support himself, he's had to live and work and cook and clean, so he's not like that, I've had a very different, I've got a very different point of view (...)

I'm very independent and he allows me to be like that. He allows me to study, he forces me (...)

After my daughter died I couldn't leave the house. I was very scared and I don't know I was just afraid and was very isolated and he forcibly came and picked me up and said: 'We've got to go and take you to college and you've got to enrol on a course.' And he sat with me and I said I wanted to do Urdu because I didn't know what I wanted to do,

just playing around and he said forget that, you don't need that, you're good at English. Do something that will help you in your English. So I chose GCSE English which I'd never done, I'd never had the chance. I left school at 16 with nothing because my parents were different, you know very strict and I never had that choice of education and I never had that given to me.

(...)

(Parents) never said to me 'You have to marry him, or you have to do this, you have to do that.' No he (father) was strict as in an Islamic way but the marriage thing, he couldn't take that. He said, 'I hate it when people force their children to get married', he said 'it will not work, it's just not right, it's not the right thing to do'.

Thus in constructing her tale, she has to oppose the stereotype that Muslim women's lives are dictated by others, whether this is the husband or the father. Conversely, for some Muslims in her community 'their wrong actions are giving Muslims a bad name, the whole Asian culture, not just Muslims (...) because they act so wrongly, conducting forced marriages, it's so wrong so sinful, do you know the Islamic marriage contract is not valid if it is forced?', but she praises her relationships with Indian neighbours, whether Muslim, Hindu or Sikh: 'our apple trees bear fruit and theirs bear fruit, and we share them, this is what we do, why should people be unfair? We are not going to stay on this earth, we are not here forever'. Her striving to be ethical encompasses

taking in foster children from the wider kinship network, working hard, and taking out loans to improve themselves through study. Her mother says because she has been brought up and educated in the UK she is like a gori (white woman) and she marks the age of her terminally-ill daughter to the day 'the Queen opened the Children's Hospital after Diana died', linking her story to a female British 'celebrity-icon' (Alexander, 2010: 323).

My (nth) baby was my daughter and sadly she died

(...)

She was (n) days old the day the Queen opened the Children's Hospital after Diana died, and (...) she had (condition) and she also had thalassaemia major so I've not been very, (...) I'm very blessed that I have my children that I have and he's (son with beta-thalassaemia major) a fine young man, he's turned out to be a fine young person.

She distances herself from those whose 'wrong actions are giving Muslims a bad name' and strives to live an ethical life, eschewing a reliance on a social security payment when she feels it is no longer appropriate. 'I took him off DLA because I couldn't lie, as a Muslim', because, although when her son was younger she needed to stay up twelve hours every night and he needed special educational needs support at school, he had developed and now needed far less support.

She recounts regular visits to hospital outpatients, attending several different departments on each visit ('you're going up, down, it was a horrible system') with young children in tow ('it was a nightmare, it was like carrying whole house. You had your pushchair, your pram, your children, all their belongings that they liked and things, their bottles, it went on and on and it was a very difficult time'). When offered a bone marrow transplant for her son with beta-thalassaemia major she was already 'very touchy, touchy raw' from the wearing, stressful hospital visits and her daughter's death when 'it was put to me (consultants) have a competition between themselves about who is doing better (in terms of numbers of bone marrow transplants)'. In the context of this life-story, struggling in terms of limited material resources, fighting both stereotypes of her culture, but also resisting aspects of her culture, her reproductive decision-making, as someone with thalassaemia trait, is explicable neither in terms of fatalism nor ignorance (see also Ahmad et al, 2000).

I just couldn't do it (amniocentesis as prenatal diagnosis), religion and leaving it to Allah, leaving it to God.

(...)

Leaving it to God and you understand where I'm coming from. So a lot of things played a key part in that and to just leave it, let it be, because my husband and me we have a good ten year gap, he's ten years older than me and we just couldn't (...) it was just

causing a lot of conflict between us and we couldn't, we didn't know how, what to do.

We were very torn.

(Interviewer: Can I ask you why it was causing conflict? Was it difficult just because when families face a difficult time..?)

It was difficult because we didn't want, we didn't want to lose the baby. No matter what we didn't want to lose the, risk (...) the baby because we don't even know if the child has got the disease and it's not up to us.

Nowhere in our transcripts was Ricoeur's claim, that stories are about ethical struggle, illustrated more fully than here, as the mother re-fuses three levels of experience – the tiredness of bodily symptoms of anaemia, the weariness of accomplishing family life and the strain of resisting both stereotypes of being a Muslim and distorted demands of being a Muslim in British society. In Bruner's terms she is creating turning points in her narrative, turning points that "mark off the narrator's consciousness from the protagonist's" (Bruner, 2001: 32), meaning that she ceases to be a recorder of history and signals a desire to be agential in changing futures for mothers of thalassaemia children and for Muslim women in the UK.

Conclusion

Ricoeur attends to how we make sense of ourselves as embodied beings, in relationships to others and in social relations with groups. What is remarkable in the narratives of those with sickle cell or thalassaemia trait is that, to a greater or lesser extent, the participants have woven together ideas at the level of their embodied selves, their social relationships with kin, neighbours and community members, and wider socio-cultural relations. To make sense of sickle cell/thalassaemia trait is to create a narrative that encompasses all these domains and integrates them into a coherent whole. What medical genetics abstracts and de-fuses, the practice of narratives contextualizes and re-fuses. Often as with Naeema or Abiola, such narratives are also about challenging misrecognition (Bourdieu, 1977), whether this be the misrecognition of Muslim men, of post-slavery racism, or, simply, of being a genetic carrier.

Moreover, the resulting narratives are performed in such a way as to weave the elements together into a coherent narrative thread, whilst seeking to be ethical, to resolve the question of how should I live a good life? Such narratives further address themselves to misrecognition by others. To an extent there is an integration of imaginative narrative into actual lived experiences, that is, to integrate hypothetical 'preferred realities' (Freedman and Coombs, 1996) within current lives. Finally, with narratives conceived as purposive challenges to misrecognition (Schiff, 2014),

we can begin to discern the goal of narrative practices. The purpose is to achieve an integration of imaginative narrative into actual lived experiences, that is, to instantiate 'preferred realities' within current lives, sustaining the human hope of transforming such lives. Carter and Charles (2013) suggest that what makes us human is a grammatical language capable of imagining a collectively different life. Narratives are thus not only about an ethical personal life but project the preferred realities of communities aiming at a collective better future.

Narrative practices enable an imagining other alternative socio-political or socio-cultural arrangements (without oppressive post-colonial power relations, without government hegemony over family life, without one's life being over-determined through attribution by others to a static place in an ethnic group, religion or culture). Narratives on sickle cell/thalassaemia trait remind us that the health encounter is a moral domain, that genetic information is a de-fused fragment of a life, one that people struggle to re-fuse into an ethical life course, a life where many legitimate virtue ethics are possible, ethics hypersensitive to slight changes in context, and only knowable through the painstaking mutual discussion currently absent in time-pressed health encounters.

There is a disconnect between practice, and the understanding and expectations of people with sickle cell or thalassaemia trait. We have three policy suggestions. First, trait carriers interpret material about their bodies beyond reproductive risk, in ways not anticipated by health care

professionals, who then make judgements about an individual's interpretation within conventional bio-medicine, to undermine people's interpretations. The discourse on the (denied) connection between trait and symptoms is an example of this. Yet as the US experience demonstrates, carrier status is accorded meaning within racist contexts, denying people opportunities (Carter and Dyson, 2015). We need to recognize the contextual merits and demerits of public health advice that trait is benign, and, recognizing that public health and patients-as-individuals comprise different constituencies, engage with the personal troubles of the individual.

Second, professionals could recognize that informed choice in reproductive decision-making is not theirs to impart, given other social imperatives in people's lives, and reframe their task as providing *informed reproductive care*. To extend Ricoeur, justice also depends on entitlements of the subject, on *positive freedoms*. *Informed reproductive choice*, the stated goal of identifying genetic carriers of sickle cell/thalassaemia in England, is based on *negative freedoms* (people are not prevented from choosing prenatal diagnosis and termination) not on *positive capabilities* (could people *actually* ignore cultural imperatives for children, muster the resources to care for a disabled child, and simultaneously resist racism, disability discrimination and the gendered order of society?). But care is an emergent moral property of social relationships and, as such, cannot be a pre-judged activity (Chattoo and Ahmad, 2008). Choice forecloses; care presupposes an intentionality of openness.

Third, in seeking to insert such grand narratives into the life-worlds of people characterized being sickle cell or thalassaemia genetic carriers, biomedicine turns an ethical mystery (how will I remain true to myself and accountable to others in the face of having the trait) into a moral problem (should I consider selective termination). By contrast our style of questioning co-produced the narratives in the sense that it topicalized physical symptoms, but without foreclosing the authenticity of such claims. It solicited opinions of genetic screening for different stages of the life-course, contextualized in different biographies, thus encouraging an exploration of virtue ethics rather than answers to an imposed moral dilemma. It opened the possibility for people to create links to broader societal relations, to broader injustices affecting themselves and their communities, broader injustices compelling themselves and the reader towards a public, political, engagement.

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References

Ahmad WIU, Atkin K. and Chamba R. (2000) 'Causing havoc to their children?' Parental and professional perspectives on consanguinity and childhood disability. In: Ahmad WIU (ed) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press. pp. 28-44.

Atkins K (2005) Paul Ricoeur. *The Internet Encyclopedia of Philosophy* Available at: www.iep.utm.edu/ricoeur (accessed 28 January 2016).

Alexander JC (2006) Cultural pragmatics: social performance between ritual and strategy. In: Alexander JC, Giesen B and Mast JL (eds) *Social Performance: Symbolic Action, Cultural Pragmatics, and Ritual* Cambridge University Press. pp. 29-90.

Alexander JC (2010) The celebrity-icon. *Cultural Sociology* 4(3): 323-336.

Bourdieu P (1977) *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Brockmeier, J and Carbaugh, D (2001) Introduction. In: J. Brockmeier and D. Carbaugh (eds) *Narrative and Identity: Studies in Autobiography, Self and Culture* Amsterdam, Philadelphia: John Benjamins Publishing Company, 1-22.

Bruner, J (2001) Self-making and world-making. In: J. Brockmeier and D. Carbaugh (eds) *Narrative and Identity: Studies in Autobiography, Self and Culture* Amsterdam, Philadelphia: John Benjamins Publishing Company, 25-37.

Carter B and Charles N (2013) Animals, agency and resistance. *Journal for the Theory of Social Behaviour* 43(3): 322-340.

Carter B and Dyson SM (2011) Territory, ancestry and descent: the politics of sickle cell disease. *Sociology* 45(6): 963-976.

Carter B and Dyson SM (2015) Actor Network Theory, agency and racism: the case of sickle cell trait and US athletics. *Social Theory and Health* 13(1): 62-77.

Chattoo S and Ahmad WIU (2008) The moral economy of selfhood and caring: Negotiating boundaries of personal care as embodied moral practice. *Sociology of Health and Illness* 30(4): 550-564.

Chattoo, S (2015) Interactional analysis of in-depth interviews: interpreting ideas and experiences of genetic risk. London: Sage. Available: <http://dx.doi.org/10.4135/978144627305014541622> [accessed June 2nd 2016]

Chernilo D (2014) The idea of philosophical sociology *British Journal of Sociology* 65(2): 338-357.

Clark JA and Mishler EG (1992) Attending patients' stories: reframing the clinical task. *Sociology of Health and Illness* 14(3): 344-71.

Dingwall R (2001) Contemporary legends, rumours and collective behaviour: some neglected resources for medical sociology? *Sociology of Health and Illness* 23(2): 180-202.

Farrell MH and Christopher SA (2013) Frequency of high-quality communication behaviors used by primary care providers of heterozygous infants after newborn screening. *Patient Education and Counseling* 90(2): 226-232.

Frank AW (1995) *The Wounded Storyteller. Body, Illness and Ethics*. Chicago: Chicago University Press.

Freedman J and Coombs G (1996) *Narrative Therapy: The Social Construction of Preferred Realities*. New York: W.W. Norton.

Fulwilley D (2011) *The Enculturated Gene: Sickle Cell Health Politics and Biological Difference in West Africa*. Princeton, NJ: Princeton University Press.

Hallowell N (1999) Doing the right thing: genetic risk and responsibility. *Sociology of Health and Illness* 21(5): 597-621.

Kai J, Ulph F, Cullinan T, and Qureshi N (2009) Communication of carrier status information following universal newborn screening for sickle cell disorders and cystic fibrosis: qualitative study of experience and practice, *Health Technology Assessment*, 13, 57, <http://www.journalslibrary.nihr.ac.uk/hta/volume-13/issue-57>

Layder D (1998) *Sociological Practice: Linking Theory and Social Research*. London: Sage.

Marcel GH (1951) *The Mystery of Being, vol.1, Reflection and Mystery*. Translated by GS Fraser.
London: The Harvill Press.

Medved MI and Brockmeier, J (2008) Continuity amid chaos: neurotrauma, loss of memory and sense of self *Qualitative Health Research* 18(4): 469-479.

Merleau-Ponty, M (1969 [1964]) *The Visible and the Invisible* Evanston, Ill: Northwestern University Press.

McLaughlin J (2015) Family ties in genes and stories: the importance of value and recognition in the narratives people tell of family. *Sociological Review* 63(3): 626-643.

Munro R and Belova O (2008) The body in time: knowing bodies and the 'interruption' of narrative. *The Sociological Review* 56 (s2): 85–99.

Nettleton S (2006) 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms. *Social Science and Medicine* 62(5): 1167-1178.

Oikkonen V (2009) Narrating descent: popular science, evolutionary theory and gender politics.
Science as Culture 18(1): 1–21.

Ricoeur P (1967 [1960]) *The Symbolism of Evil*. Translated by Emerson Buchanan. Boston: Beacon.

Ricoeur P (1988 [1985]) *Time and Narrative* Vol 3 Translated by Kathleen Blamey and David
Pellauer. Chicago: University of Chicago Press

Ricoeur P (1992 [1990]) *Oneself as Another* Translated by Kathleen Blamey. Chicago: University of
Chicago Press.

Ricoeur P (1996) Reflections on a new ethos for Europe. In: R Kearney (ed) *Paul Ricoeur: The
Hermeneutics of Action* London: Sage. pp. 3-13.

Ricoeur P (1998 [1995]) *Critique and Conviction: Conversations with François Azouvi and Marc de
Launay*. Translated by Kathleen Blamey. Cambridge: Polity Press.

Rothman BK (1993) *The Tentative Pregnancy*. New York: WW Norton

Sayer A (2005) *The Moral Significance of Class*. Cambridge: Cambridge University Press

Skeggs B (2014) Values beyond value? Is anything beyond the logic of capital? *British Journal of Sociology* 65 (1): 1-20.

Schiff JL (2014) *Burdens of Political Responsibility: Narrative and the Cultivation of Responsiveness*.
New York: Cambridge University Press.

Table 1: Respondents

			Self-Reported Ethnicity and Religion	Trait
1	Lilian	F	Jamaican/African (Methodist) Grandmother Syrian/mixed heritage	S
2	Mamokoh	F	Born Sierra Leone (Dad mixed heritage) Married to White man	S
3	Mary	F	Born in Ghana. Came to UK in 1980s (Anglican)	β
4	Carol	F	Mixed (White/Caribbean)	β
5	Beryl	F	Black Caribbean	S
6	Barrington	M	Black British (both parents Jamaican). Born UK	S
7	Iyanda	F	British Nigerian. Born UK	S
8	Cecilia	F	Black Caribbean. 9 years old when moved to UK. (7th Day Adventist)	S
9	Abiola	F	Nigerian (Christian) Moved to UK in mid-30s	S
10	Jackie	F	White British (Church of England)	β
11	Deisha	F	Black British, Mixed Heritage. Born UK (Jehovah's Witness)	S
12	Dalton	M	Mixed ethnic heritage on both sides of family {Jehovah's Witness}	S
13	Emmanuel	M	Black British. Mixed Heritage (Jamaican/Nigerian)	S
14	Nora	F	Black British. Born UK. Mixed Heritage (Jamaica/Indian)	α
15	Donald	M	Black British. Born UK. Jamaican parents. White partner	S
16	Winston	M	Born in Jamaica. Moved to UK when 11 years old	S
17	Isad	F	Pakistani. Born UK (Muslim)	β
18	Tariq	M	Pakistan. Came to UK to marry. (Muslim)	β
19	Madan	M	Pakistan Kashmir. (Muslim)	β
20	Marcia	F	Black Caribbean. Born UK. (Christian)	S
21	Samuel	M	Black Caribbean. Born UK (Brought up Christian)	β
22	Kojo	M	Family for Ghana. Born UK. (Pentecostal Christian)	S
23	Rafia	F	Pakistan. Born Azad Kashmir. Came to UK at 10 years old	β
24	Dhuka	F	Pakistan. Born Azad Kashmir. Came to UK following marriage (Muslim)	β
25	Faarooq	M	Pakistan. Born Azad Kashmir. (Muslim)	β
26	Amina	F	Somalia. Moved 12 years ago to UK	S
27	John	M	British African. Born UK. Mixed (Jamaican/Dominican) (Christian)	S
28	Habiba	F	Pakistan. Born Azad Kashmir. Moved to UK 28 years ago. (Muslim)	β
29	Nafiah	F	Born Pakistan. Moved to UK when 2 years old. (Muslim)	β
30	Jacob	M	Black British. Born UK. Parents of Caribbean origin.	S
31	Basheera	F	Azad Kashmir. Born UK. (Muslim)	β
32	Naeema	F	Pakistani. Born UK. (Muslim)	β
33	James	M	Black British. Jamaican origin. Moved to UK at 5 years old (Baptist)	S
34	Lamont	M	Jamaican	S

35	Tahera	F	Indian-Gujarati. Muslim	β
36	Tejinder	F	Indian Punjabi (Sikh)	β
37	Waheed	M	Pakistani, Rawalpindi. Moved to UK a few years ago (Muslim)	β
38	Naazneen	F	Pakistani. Moved to UK aged 14. (Muslim)	β
39	Sakina	F	Pakistani, Jelum. Born UK (Muslim)	β
40	Randall	M	Caribbean. Born UK (Jehovah's Witness)	S
41	Linda	F	African-Caribbean. Born UK	S
42	Emmanuel	M	Black African. Born Sierra Leone. Moved to UK after marriage.	S
43	Tayo	M	Nigerian (Christian)	S
44	Vahini	F	Indian-Gujarati (Hindu)	β
45	Rosa	F	Mixed Heritage (Portuguese Catholic+Turkish Cypriot Muslim)	β
46	Duman	M	Turkish-Cypriot (Muslim)	β
47	Maria	F	Greek Cypriot (Greek Orthodox). Partner White	β
48	Andrea	F	Mixed Heritage, English-Greek (Greek Orthodox)	β
49	Satwinder	F	Indian Punjabi (Sikh)	β
50	Anina	F	Indian Gujarati (Hindu)	β
51	Mahmood	M	Indian Gujarati (Muslim)	α
52	Huri	F	Turkish Cypriot. Moved to UK aged 7. (Non-practicing Muslim)	β
53	Anne	F	Greek Cypriot (Christian)	β
54	Theo	M	Greek. Born UK (Greek Orthodox)	β
55	Giannis	M	Greek Cypriot. Born UK. (Greek Orthodox)	β
56	Alex	M	Greek Cypriot. Born UK (Atheist)	β
57	Osman	M	Nigerian (Muslim)	SCD
S = Sickle cell trait; β = Beta-thalassaemia trait; α = Alpha-thalassaemia trait; SCD = Sickle Cell Disorder				