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## **Critical Realism, Agency and Sickle Cell: Case Studies of Young People with Sickle Cell Disorder at School**

### **Abstract**

Critical realism suggests that historical structures may operate as underlying generative mechanisms but not always be activated. This explains the near-absence of references to racism by black students with sickle cell disorder (SCD). Through case studies we show how latent mechanisms are not activated, and how social actors come to develop corporate agency. Themes discussed include: *wider/historical racisms* (carers' own experiences of overt racism at school); *conscious actions* (moving away from a school where racism was experienced); *awareness of anticipatory retaliation* (multiculturalism as a form of societal inoculation against accusations of racism), *naming racism as an emergent strategy* (when communal discussions enable multiple negative experiences to be framed and named as racism), and "*passing*" (not ostensibly experiencing racism if one is sufficiently light-skinned). Critical realism suggests how racism may be structuring the experiences of students with SCD at school even in the absence of specific accounts by young people.

**Keywords:** sickle cell; racism, agency, critical realism, case study, schools.

## **Introduction**

Sickle cell disorder (SCD) is a complex chronic illness, which in England is more common in those of Black African/Caribbean descent. Young people with SCD report extensive negative experiences in their school lives (Dyson et al, 2010) and it is important to ascertain the extent to which disability discrimination or racism contribute to these experiences. In this article the authors suggest a theoretical position for understanding the subtlety of racism in structuring the lives of young black students with SCD even in the absence of any reported racism. Racism is conceived of as an ideational phenomenon deriving its power through specific socio-political interactions (such as slavery) which leave historical-material and cultural-ideational structures that constrain subsequent interactions (Carter, 2000). This conception of racism derives from the broader theoretical position of critical realism. We first outline this theory of critical realism. We next describe our research programme of the experiences in school of young people living with SCD, within which the ten case studies we consider are situated. We suggest racism cannot be assumed to be absent on the basis of the lack of explicit references to the phenomenon, and consider the subtle ways racism structures school experiences.

## **Critical Realism and Racism**

Critical realism is a philosophy underlying social research. The social world is conceived as having ontological depth, with three realms: the observable, the actual (hidden from immediate interaction but observable in principle), and the

realm of the real, comprising structures, unobservable, even in principle (Bhaskar, 1979). Such structures might include capitalist relations of production or post-colonial relations. Following Layder (1990), *social relations* (structures) of discriminatory practice are not directly observable (and so may be opaque to individual actors), though *social relationships* between black students and white teachers potentially are. There is a distinction between experiential common sense language (race) and social scientific analysis of racism (Carter, 2000). Critical realism involves “a plausible case for the existence of unobservable entities [...] by reference to observable effects which can only be explained as the products of such entities” (Sayer, 2000, p. 12). There is an analytic distinction between studying structure and studying agency, avoiding reducing one to the other (Archer, 1995). Thus practices that have discriminatory effects are to be analysed separately from racist ideational resources, without reducing one to the other. Institutional racism as a concept conflates discriminatory practices and the ideational resources of racism and thus the need to examine the interplay between the two. Whether a discriminatory outcome is racist is a (difficult) empirical question of the specific relationship between what people do and what people think (Carter, 2000). Research involves not making a priori assumptions about the saliency of particular concepts (Pawson and Tilley, 1997) and we suspend any prior assumption that the effects of practices can be specifically traced to racism, not least because young people with SCD may experience discrimination based on their chronic illness. As we shall see, the participants in our research also struggle to make sense of particular instances of inter-relations between discriminatory outcomes and racist ideas.

Archer (1995, 2003) suggests an important distinction needs to be drawn between considering people as social actors and people as agents. A social actor is current, singular, and involves individual actions in the present. Agency on the other hand is plural, relational, and dependent upon what has happened in the past. Agency then depends upon an historical-material positioning of people as collectivities, a positioning that entails a distribution of potential social roles that are available and an associated enabling or disabling of capacities for action. Furthermore, whilst even animals have primary agency, only humans (potentially) have corporate agency, by virtue of possessing a grammatical language capable of sustaining a collective imagining of political alternatives (Carter and Charles, 2013). As we shall suggest, part of what it means to name and recognize racism depends upon developing corporate agency. Archer (1995) also works with the notion of a morphogenetic cycle, in which previously elaborated historical relations (material structures and cultural ideational resources) at stage one (point of time one, or  $T_1$ ) are a given antecedent to social interactions at stage two ( $T_2$ ), which interactions modify the situation ( $T_3$ ) and come to constitute the given social antecedents of the next cycle (see Carter, 2000, pp. 98-137 for an applied example). The themes we draw out of our data are not all equivalent and index different stages of the morphogenetic cycle.

Early studies of classroom interaction suggested that racism was in evidence in social relationships within school (Wright, 1992; Hatcher and Troyna, 1993), but were criticized for assumptions that accounts of racism could be treated, *prima facie*, as evidence of racism in schools (Stevens, 2007). Other studies have suggested that the media and the Department for Education

misrepresent relative achievement data (Gillborn, 2008); that black women teachers are marginalized (Ladson-Billings, 2009), and that white teachers-in-training actively resist the acquisition of skills necessary to relate to young black people (Picower, 2009). Such critical race theory (CRT) studies alert us to the possibility that racism may potentially be influencing school encounters through mechanisms at a distance from classroom interactions.

Moreover, given aspirations within CRT to analyse intersectionality (Gillborn, 2008), there are practical reasons why it may be necessary to demonstrate, rather than to assume *a priori*, the primacy of racism in framing the experiences of young black people living with SCD in school. First, one precursor of a resistance to racism is a careful delineation of which negative experiences can be unambiguously categorized as racism. For example, Caribbean nurses coming to the UK in the 1950s developed resistances that depended on distinguishing between racism and discriminatory outcomes based on gender, age, or relative occupational status (Culley et al, 1999). This is not to deny that stereotypes may be co-constructed through the intersection of, say, gendered relations and racism (Ladson-Billings, 2009), but it does suggest that discriminating between different forms of oppression helps people retain a coherent sense of identity, something young people living with SCD struggle with at school in the face of multiple oppressions (Dyson et al, 2011). Secondly, schools find it challenging to be inclusive of young people with chronic illnesses (Mukherjee et al, 2000), and teacher/pupil response to illness is a key mediator of pupil accounts of racism (Stevens, 2009). Without first suspending judgement on the crucial specific structures at work (and thus avoiding an

analysis of racism to be suppressed by the accusation that the phenomenon ‘merely’ entails colour-blind disability discrimination), we cannot adequately demonstrate the workings of racism in less obvious ways. Thirdly, we feel our approach lessens the potential for the testimony of black community activists to be used against them. In presenting findings to an audience of fifty activists at the 2010 Sickle Cell Disease Association of America Annual Conference, the audience consensus was that the negative experiences of young people with SCD at school in England (Dyson et al, 2010) were also present in the USA in predominantly black schools with predominantly black teachers. Whilst we do not take this as evidence that racism is not there in the experience of young people with SCD at school, we feel there is a danger that this is precisely the message that could be inferred were one not able to make the case for racism being apparently absent but really underlying events.

## **Methods**

Our data forms part of a multi-method study into the experiences of young people with SCD at school. This comprised a survey of 569, and in-depth interviews with forty young people living with SCD (two aged under 11, thirty aged 11-18 and eight aged 19-25). The interviewees were drawn from 200 volunteering for interview from the 569 questionnaires. The forty were chosen for diversity in reported level of school success (Dyson et al, 2011). Interviewees recounted a lack of appropriate support and care. However, it was not possible from the accounts to attribute teachers’ reported (in)actions

concerning students with SCD as *necessarily* deriving from stereotypical views of black students which then intersected with SCD symptoms to further disadvantage students with SCD. Indeed, across the forty interviews there was only one explicit reference to racism, and this instance was put aside from the main analysis (Dyson et al, 2011) for follow up in the case study phase of the research that forms the basis for this paper.

Young people with SCD were selected for the case studies on the basis of dimensional sampling (Cohen et al, 2007). We approached fourteen respondents, ensuring we had male and female respondents of Black African and Black Caribbean descent. Two Black Caribbean males, said by our intermediary to be particularly disaffected with school, declined to take part, and two Black African females withdrew because of illness. This left ten young people. For two young people we used a pre-existing interview collected with the young person as part of the original forty interviews. For the other eight young people, the interview was newly conducted in the case study phase of research. The ten participants are described in Table 1.

[Table 1]

Each participant gave a recorded interview of thirty to sixty minutes, as did each main carer (usually the mother; in one case a voluntary sector worker, and in one instance both mother and voluntary worker). The case study interviews with the young people and their carers followed the same topic guide as the original set of forty interviews, focusing on experiences at school related to SCD, with

the deliberate addition of a question asking about racism. Each young person was given a digital recorder and asked to keep a diary of their school experiences over two separate periods of two weeks. The interviews were transcribed in full by the researcher conducting the interview. Field notes were taken of meetings involving the researchers (for example, negotiating access through self-help groups or leading seminars feeding back to community members the results of the research). These notes were based on observations and informal conversations, and were written up from memory the day after the event.

The transcripts were grouped by participant so that young person interviews, carer interviews and diary entries referring to the same young person were juxtaposed, and a complete set circulated to all authors for review. The forty-five instances referring to racism within the data were written out in long-hand, and with critical realism as an explicitly conceived theoretical foil, were grouped together into four broad themes.

The four themes were: (1) *Wider Racisms*: the idea that historical/wider racisms in society would, without specific remedial challenge, impact on the localized setting of school relations; (2) *Conscious Strategies for Disabling Racism*: the carer undertaking conscious work or being mindful that strategies were required in order to neutralize, avoid or disable the mechanism through which racism might otherwise have been instantiated; (3) *Awareness of Anticipatory Retaliation*: multiculturalism was conceived as a form of societal

resistance to anti-racism, protecting wider society from having to engage in a more thorough and critical examination of social practices, and (4) *Naming Racism as an Emergent Strategy*: learning to discriminate between racism and other negative social relations, to identify commonalities and generalize appropriately to a named concept of racism, and to find ways to resist racism, were learned behaviours that depended upon networks emerging within and between black professionals, black parents and young black people. Finally, under the heading *Pigmentocracy and Passing* we also revisit the single reference to racism in the original set of forty interviews and note that lighter skin may enable some young people with SCD to circumvent mechanisms of racism that might otherwise be enacted. We now look at each of these themes in turn.

### **Wider Racisms**

It might be argued that racism in British schooling is largely ‘in the past’ and that this is why it does not feature in the forty original interviews with young people with SCD. However, actions may be in the present, but be constrained by social structures generated in the past (Archer, 1995). None of the young case study subjects themselves explicitly mentioned racism in their interviews, though five mentioned teacher accusations of being lazy when tired (from anaemia: a central symptom of SCD), which at the very least dovetails into racist stereotypes of laziness (Tikly et al, 2006), and only Clinton (twice) used the term ‘racist’ in his diary in the context of describing bullying by others.

By contrast seven of the carers referred to their child's experiences at school as evidencing racism ('Mum I love you but I don't want to be your colour because if you're white you're better treated') and seven recalled overt racism in their own experiences (discrimination in education or employment, being stereotyped as aggressive or unintelligent; or their history subjected to the most base distortions - from living in trees, through to assertions from teachers that England had never been part of the slave trade). This suggests to us that the majority of the parents conceptualize a social world for their child that, without active intervention, will continue to reproduce racism by default. This may be why the mothers feel that their experience of past racism is an important resource in their role as adults in interpreting situations to young people:

**Clinton's Mother:** Well if they feel that somebody is saying something about them they shouldn't be saying, then/ (...) bring it back to your parents to give you coping strategies for where to take it to next./ Yes, I do think so, take it back to your parents (...) or go to an adult you can trust, that you can talk to and say, well look, this has happened and I believe it's a racist remark, what do you think? I mean get the advice from them.

However, whatever the situated activity within the school, the school is set within a wider society, and without specific counterpoints, any wider racism becomes, by default, part of an allegedly natural state of affairs. Jemima's mother comments:

Because I think racism is subtle; racism is about breaking down your confidence and your identification with anything positive to do with your race. I mean, I had two black children in a predominantly white country. If you see anything on television it's putting black people in a negative light: lazy, drug-pushers, knife-wielding youngsters; if you

hear the news they're always going on about black on black crime; blacks killing each other. Where is all the positive imagery of the positive things that black people and black children are doing within this society?

In this short extract from what is a wide-ranging account, she claims that wider negative images of black people in the media, in criminal justice, in education, in politics, in self-identity, and the absence of Black History means that 'my children are faced with the more subtle prejudice that's going on in people's minds'. In Archer's terms this theme could be said to refer in time to  $T_1$ , the historical-structural factors that render subsequent actions conditional. The implication is that it therefore requires perspicacity to read the meanings of individual experience in the light of (what could be to the young person opaque) social structures and respond accordingly. This brings us to the next theme.

### **Conscious Strategies for Disabling Racism**

One type of activity reported to us involved the black carers in conscious action. This theme might be said to refer to the cultural actions that take place in the context of the wider structures (Archer's  $T_2$  stage of the morphogenetic cycle). At first the mother's account focuses on her son's SCD: he is big for his age, has difficulty in squeezing into primary school-size furniture and has resulting sickle cell pains in his legs. But Anthony's mother goes on to recount that:

The first school he went to (...) we had some problems with the teachers. That was really based on the relationship between my husband and the teachers. It was a very white

middle-class school, and as a black child moving into the area (...) I think they felt quite threatened if I'm going to be to be blunt, about my husband, six foot, black man. They didn't know how to deal with him; he was asking a lot of questions, taking an interest – they didn't want to know, yes? (...) we had to withdraw Anthony because he was getting depressed (...) found another primary school where he started to settle down.

She suggests that the white middle class school is ill-prepared to educate a young black student, that teachers appear 'threatened' by the mere presence of Anthony's father (drawing on notions that the black male signifies potential aggression) and, moreover, that this perceived threat is amplified by the fact that the father does not conform to a (racist) stereotype, namely that (black) fathers are expected to have minimal involvement in the emotional work of school liaison. Rather, Anthony's father takes a very active interest, and this breaking of gendered roles, in which the mother is expected to undertake the emotional labour of home-school co-operation (Reay, 2004a), also appears, in the account of the mother, who specifies 'six foot, black man,' to be racialized by the school staff. In addition, the mothers of Duane, Grant and Henry also suggest that children with SCD do not articulate the notion of racism because of the predominantly black neighbourhood and ethnic profile of the school.

This conscious and pre-emptive action extended to other parts of our multi-methods research, and field notes taken at a community seminar produced a comparable example:

(He) indicated his caution as a black father advocating for his son at school. (...) he was perceived by (presumably White British) teachers as physically powerful and aggressive. He said his culture (Nigerian) led him to speak out loudly and gesticulate with much

animation when talking to others. He contrasted this with “your” (presumably White British) culture of being understated and non-expressive. He said he recognized these attributes in himself and quietened his voice and downplayed his expressiveness when communicating with school authorities so as to reduce the possibility of the stereotype of the aggressive black male that might otherwise be called into play. [Field notes, 29 May 2010]

The father recounts how he deliberately adapts his interpersonal demeanour in dealings with school authorities, conscious of how one mechanism of racism could be operationalized. The work of achieving apparent concordance is achieved by the black father rather than the white teachers.

A further type of conscious strategy concerns the expressed view of three mothers (Anthony, Beatrice and Jemima) that SCD should be de-coupled from its association with being black.

**Beatrice’s Mother:** they need to be more aware, especially at school (sighs)/ not just the teachers, you’ve got the other staff as well, need to be aware that (...) it’s not just the ‘black’ thing they perceive it to be.

The implication seems to be that it is the framing of the issue as a black issue rather than as a health issue that is behind the lack of responsiveness to health needs of young people with SCD at school. Contrary to popular perceptions, the sickle cell gene is not absent in white groups. Even within the UK census category “White British”, 1 in every 450 children born in England carries a gene relevant to sickle cell. But in England most (97 per cent) young people living with the chronic illness SCD described their ethnicity, when given

a choice of UK Census categories, as Black African/Caribbean/Other (Dyson et al, 2010). The challenge is not just that SCD is seen as a “black disease” (Anthony’s mother), but that in a racist society this association evokes a series of negative connotations of being black that also then attach to SCD (see Bediako and Moffitt, 2011).

The final conscious intervention we consider here, supplementary schooling, has a long history. Black supplementary schools have been considered as more than merely extra mainstream tuition, but rather as decentering assumptions about what should, and what should not be culturally valued in knowledge and learning (Mirza and Reay, 2000).

On Monday I had a math retake so I had to revise over the weekend. I have to start next week, I have to go to Saturday school to help me with my maths and GSCE. So it is going to be a bit hard having an extra school day. (Francesca’s Diary, Recording 11)

The increased emphasis on measuring relative attainment of schools and their pupils (Gillborn, 2008) may however mean that Saturday schools experience a pressure towards instrumentalism in preparing for mainstream exams (Francesca’s Saturday school is to help with GCSE, a standard public examination) at the expense of specifically black supplementary schools whose ethos offers a paradigmatic challenge to racism. The increasingly neo-liberal context of education may mean that strategies of redress are becoming increasingly individualized and that extra tuition on a one-to-one basis may become more common. Henry’s mother mentioned extended family members who gave extra tuition and three mothers (Anthony, Beatrice and Jemima)

mentioned trying on an individual basis to impart Black History to their children.

It is difficult to conceive how these social actions might come to be represented in the accounts of young people with SCD at school. The self-conscious actions of the parents, removing their son from an (initially) desirable school and subsequently choosing a school with a high proportion of black pupils would not necessarily feature in the accounts, ten years later, of a young person explaining their challenges of living with SCD. Meanwhile, decoupling SCD from its association with being black seems potentially at odds with other conscious strategies such as black supplementary schools, imparting Black History or other strategies that assert black political identities as normative.

### **Awareness of Anticipatory Retaliation**

This next theme concerns what might be consequences of making claims of racism in specific contexts. Francesca's mother felt that she had experienced racism when a teacher accused her daughter of leading others astray. Francesca dissuaded her mother from challenging this because she was growing accustomed to not being listened to, perceiving that teachers helped white pupils but not black pupils. Grant's mother also develops a sense that young people may be anticipating negative consequences of naming experiences as racism:

**Grant's Mother:** ...the kids of today are not going to be putting up with racism. So, even though they know, they are probably gonna be subjected to racism, they're just

gonna deal with it in their way; they're gonna deal with the teacher regardless; they're gonna tell the teacher what they think (...) they're not necessarily gonna say it's racism they're just gonna deal with them verbally and articulate their point regardless. They might wanna talk about it being racism afterwards (...) I know my kids come home and say things that are clear cut racism. Maybe they're not gonna say clear cut racism to the school because they don't know how the school's gonna treat them after (...) you know once they start crying racism, they probably think (...) they're not gonna be dealt with in the school properly,

The mother suggests that she hears reports of 'clear cut racism', but that the young people's responses, though robust, may not draw specifically upon that concept. The term might be used in the safety of peer groups afterwards, but it is not the vehicle for making representations to school staff as they fear invoking the term would itself lead to the issue not being properly addressed. In the context of discourse analysis Potter (1997) has developed the idea of 'stake inoculation'. Since most utterances carry an implied commitment to a certain moral position, in certain special contexts people find a form of words that avoids taking an explicit position and thus inoculate themselves from being held to account for any particular position or stake. Consider the following quotation

**Clinton's Mother:** I think it's down to society. Oh we live in a multi-racial society; oh there's no racism, there's no racism, racism? No, we love all our friends; I've got black friends, I'm not a racist. You hear that so often, the kids are scared to say. Oh that was a racist remark miss. "Oh no we don't have that in our school, we don't have that in our society". But there are racists.

Clinton's mother portrays multiculturalism as a form of societal inoculation against accusations of racism, making young people scared to articulate claims of racism because the school is multicultural and to make a claim that racism is occurring in a multicultural context can be portrayed as naive or misguided. This socio-cultural interaction produces new conditions, conditions that damp down imagined alternatives and leave social actors in invidious double-binds where actions can be construed as illustrative of racist stereotypes (aggressive, questioning, confrontational) and inactions as confirming the lack of any need for a challenge to racism. Corresponding to Archer's T<sub>3</sub>, this theme entails a particular stage of the cycle, one illustrative of morphostasis, of why social change is less likely to occur. But a great deal of social activity, both practical and ideational, goes into achieving this stasis.

### **Naming Racism as an Emergent Strategy**

Recognizing racism is not a self-evident activity. It is not always apparent to those experiencing discrimination that they are indeed being discriminated against. Furthermore, where discrimination is recognized, it may have to be distinguished from other sources of discrimination (of age, gender, or occupational status). Thus to recognize racism one has to be cognisant of discrimination, delineate between possible forms of discrimination, and, if merited, name the experiences as racism, before resistances can be developed (Culley et al, 1999). According to Emmanuel's father, young black people with SCD may not as yet have developed the experience to distinguish between

situations they experience as generic discrimination and any particular situations that prove to be racist in character.

**Emmanuel's Father:** (...) even if it comes to them they don't understand that discrimination in its real sense as racist. But for Emmanuel the schools, primary and secondary like where he is right now, they are really looking out for it (...) all the tutors the Head and the senior ones have had that initial [programme on racial problems]. But these young ones, because they cannot [have this awareness yet] and nobody else around mentioned anything so far, maybe this is why/

This suggests that age is an important mediator in how racism is experienced. Emmanuel's father further notes that it is by having specific policies, by school staff concurring with the need to undertake policy training (though one hopes on anti-racist policies rather than on 'racial problems') and by demonstrating a commitment to challenge racism in schools that the wider racisms of society are not allowed to stand by default. The words thus suggest another possible mechanism through which potential racism may not be enacted, and that is if the school enacts robust anti-racism policies.

Furthermore, one voluntary worker interviewed, who had extensive experience in liaison work with hospitals, regards the naivety of the young people with respect to racism in schools as paralleled by their initial naivety with respect to what, for a young person with SCD, is already extensive experience of health care.

**Duane's Voluntary Worker:** Because they have not (...) seen the adult side, and where this country's concerned, children are children, and the children don't see that aspect of

it; whereas the adult now, when they go into the hospital and they see one condition being given such attention and they are waiting, they attribute maybe it's [lack of equivalent good services for SCD as for other conditions] because of the lack of knowledge and because it belongs on the black people. But the children haven't reached that level yet.

She suggests that usual discriminatory practices in the delivery of services (that adults with SCD don't get as well-resourced a service as for conditions such as leukaemia: 'that aspect of it') is suspended for children because 'children are children' and that young people with SCD only have experiences of attentive paediatric services to draw upon, and not the adult services where, she implies, they are more likely to experience discrimination, and where, without the explanation of racism, the young people with SCD would wonder why some medical conditions other than SCD appear to garner more attention. The same worker suggests the need to prepare the child to deal with racism:

**Duane's Voluntary Worker:** (...) by having discussions about it, how they feel, what they think, and what they think is acceptable and not acceptable; and be able to develop a strategy if it were to confront them, how to deal with it. Because coming to this country I never had to deal with racism like I did here, when my daughter got a (unclear) at her school. And, because I have always encouraged her to be independent, she chose for me not to deal with it.

The implication appears to be that a number of actors may need to come together, a black carer and black professional or a black mother and black child in order to develop a language, a conceptual framework that enables experiences to be labelled as examples of racism and contingent decisions negotiated as to

whether or not to take issue with that particular manifestation of the phenomenon. This theme, that communal solidarity, or even communal survival, depend on parenting-for-resisting-racism (which could be community elders, not only parents) could be taken to be an emergent property of previous collective and individual actions and thus represent the basis of the next cycle, a new T<sub>1</sub>.

### **The Single Case Revisited: Pigmentocracy and Passing**

The work of Goffman (1968), who popularized the term passing, contains several explicit references to being dark-skinned and unable (like lighter skinned people who identify as black) to pass oneself off as not black. Notwithstanding attempts to distinguish analytically between social categories of people and biological ones (Harris, 1993; Levine-Rasky, 2000), passing implies a 'true' racialized identity. Moreover, Shilling (2004) maintains that black people are especially liable, in dominant discourses, to be defined solely or principally in terms of their bodies. One way in which it would be possible for racism to inform social relations, but for racism in situated activity to be ostensibly absent, would be if one is sufficiently light-skinned to evade association with being considered black. Beatrice's mother reported that her daughter was emotionally hurt by others saying she could not be black because of the lightness of her skin, and Jemima's mother that one of her daughters had expressed a desire to use skin lightening products in order to be better treated at

school. Clinton experienced the skin condition vitiligo and associated racist abuse:

**Clinton's Mother:** Yes, he's had people call him monkey he's had (sigh) people telling him he's, what is it a leopard? Because he's got (...) the pigmentation the changing and they're calling him leopard because he's got two toned skin. It's, 'it doesn't happen to us because our skin's white'.

In the light of the enduring capacity of skin colour *per se* to play a major role in defining the nature of racism it seems pertinent to remind ourselves that, in the rush to articulate cultural racism, new racism or modern racism, all putative explanations of why 'old' racism no longer captures the changing nature of social experiences in this regard, Mason (1994) cautioned us about disconnecting racism from 'race', of analytically separating racism from flawed biological conceptions of difference.

To conclude this section, we return to our starting point, namely that in the wider set of forty interviews within the multi-method research programme on young people with SCD in schools, there was only one explicit reference to racism. This apparent absence was what prompted a specific exploration of possible reasons for this within the case studies cited. This sole explicit reference to racism in our original interviews occurred with a young woman of Black African descent aged 13, in the context of broader exchange about not revealing her SCD status to school peers.

Mother: [...] in primary school they were very good to you, if it was cold at lunchtime and playtime and you said to the teachers, I'm too cold, they'd let you stay in they didn't actually force you out. They did for your brother but they didn't force you

G11: How come?

Mother: I don't/

G11: I think they liked me

Mother: (laughs) No, no, no. My boy is nice, stop it.

[...]

Mother: You know I think that, I don't know if the researcher wants to hear this, but maybe you need to hear this, is that you're a light skinned girl and he's a dark skinned boy.

However, as will be apparent, it was the *mother* who introduced the notion of racism. The daughter herself is revealed to be puzzled why she enjoyed the support of teachers for her SCD whereas her brother was reportedly made to be outside in inclement weather, a known trigger to episodes of SCD illness. Most significantly, the mother, unsure whether racism is a relevant topic for discussion in a research interview on SCD in schools, takes the opportunity to begin to explain pigmentocracy (James, 1993) to her daughter and her explanation ('maybe you need to hear this') suggests someone who sees herself as imparting wisdom on how to recognize and negotiate racism. The exception in the original set of forty interviews is pertinent in several ways. It is the mother, not the daughter who makes a claim to recognize racism. Moreover, direct consciousness of racism is not in the lived experience of the young person herself who has good experience of support for her SCD. She does not have the contrast of her brother's experience to draw upon as does her mother, nor her mother's life experiences, including sharing and interpreting experiences with a

community of others to make sense of if and when experiences might be held to constitute racist actions.

## **Conclusion**

This article has considered whether the absence of racism in accounts of young people with SCD at school could be taken as evidence that racism was not implicit in structuring their lives. Our analysis, using critical realism, suggests racism remains relevant, but differs from critical race theory in three respects. First, sociologically, in terms of analysis it maintains an analytical distinction between discriminatory effect and racism, thereby recognizing both the opacity of social structures to individual actors, and the possibility for social actions to have unintended consequences. Secondly, this locates more accurately the nature and source of any particular problem (social relations or social relationships) as the basis for progressive political action. Thirdly, to an extent this analytic distinction *itself* characterizes the development of corporate agency by the black carers and black workers as they assess the basis for the discriminatory effect, appraise the relation of this effect to racism, and elaborate resources of anti-racism for the next generation.

Racism was not always activated in specific empirical circumstances in school because of countervailing mechanisms. The first theme suggests that *wider/historical racisms* continue to inform within-school relationships. Carers' own experiences of overt racism at school meant that they felt they had wisdom in this regard and that, without specific sustained challenges to wider racism in

society, this wider racism effectively became part of the hidden curriculum of the school. One key point about critical realism is that it allows as legitimate knowledge concepts beyond individual consciousness. In Archer's terms both the adult carers and the young people with SCD have primary agency (they are positioned by the historical conditions producing racism). However, young people with SCD do not (yet) have corporate agency. Young people might not express racism because they do not have access to any wider patterning of experience, because they have not developed an adult perspective, and, particularly pertinent to a young black person with a chronic illness such as SCD, because they have not experienced inequalities in adult health services provision, only the better paediatric provision. Only through communal discussions, encompassing black carers, black professionals and young black people, can a sense that a disparate set of negative experiences be conceptualized and named as racism emerge, and can young people with SCD begin to recognize their corporate agency.

The second theme involved *conscious actions* either on the part of the carers (moving away a school where racism was experienced; reframing their speech and bodily disposition to counteract stereotyped expectations; arguing for a de-coupling SCD from its association with a black identity where it might be vulnerable to association with imputed toxic elements of that identity; or paying for additional schooling) or, on one occasion reported, by a school adopting something akin to anti-racist policies. Here the carers recognize the role array that is made available to them and their children through their agency. They recognize the relational element inherent in their agency: they and their

offspring risk being disabled as the obverse of an enablement for those on the privileged side of a racialized divide, and specific actions are required of them to mitigate these processes.

A third way in which the mechanisms of racism may be disabled is through self-censorship, through an *awareness of the anticipatory retaliation* to claims of racism. Thus multiculturalism may be thought of as a form of societal inoculation against accusations of racism, making young people scared to articulate claims of racism; not articulating claims of racism because of the experience of not being listened to; not naming experiences racism in order to get the school to take issues seriously. Young people with SCD appear to on the cusp of recognising their agency through apprehending the flexible enabling role that relations of racism accord to dominant groups: to be the arbiters of when racism can and cannot be invoked.

Fourthly, *delineating and naming racism as an emergent strategy* is thus one further way in which the context may be altered. In such cases racism underlies events, but events at the level of individual experience appear disparate, intermittent and of uncertain provenance with respect to racism. It takes a collective community consciousness to develop a working model of what is structuring their lives. That is, it takes primary agency to be developed into corporate agency for peoples to recognize that they have social interests in common and to collectively imagine an alternative political future in which racism is challenged.

Finally, the example of the young woman with SCD and her mother in our original forty interviews suggests there is the possibility of *passing*, not (superficially) experiencing racism at all if one is sufficiently light-skinned to evade association with political blackness, a strategy that comes at the price of an ontological crisis (Fanon, 1986). What we witnessed in our original forty interviews ('maybe you need to hear this') was one small step in the primary agency of a young woman living with SCD moving towards corporate agency through the imparted wisdom of an elder.

In summary, critical realism alerts us to ways in which people act consciously (albeit with degrees of uncertainty and with unintended consequences) to change the world as it appears to others. It reminds us that what structures situated activity may be at a different ontological level to immediate school relations, such that inaction at the level of situated activity permits these wider mechanisms to surreptitiously exert ongoing effects. Learning to recognize similarities in empirical experiences and relate these regularities, in the context of community networks of support with others, to unseen forces, in short to think one can discern a connection underlying distinct empirical experiences, is a collective and learned activity: racism is not simply experienced, it is a learned way of situating yourself in the world (Reay, 2004b). In Archer's (2003) terms you recognize yourself as having agency, recognize the array of subject positions that this accords you, recognize the social roles that this accords others in relation to yourself and others like you, and finally, with experience, guidance and collective discussions that sift and sort the import of individual instances, groups may move from primary to corporate agency,

where alternatives can be imagined and collective resistances enacted. The manner in which multiculturalism can foreclose critical debate means that at the level of experience students with SCD (and other black students) learn to be docile, and the mechanisms of racism are disabled by self-censorship as students are disciplined to be good multicultural citizens. The manner in which bodies, in particular skin colour, have been instantiated into social categories means that the light-skinned may come to recognize an invidious choice: accept the minimal advantages that accrue to them or be categorized with the dark-skinned. Young people with SCD do not foreground racism in their accounts of life at school in the UK. But critical realism can help to understand how racism may be structuring their experiences even in the absence of apparent overt incidents.

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*Table 1: The Respondents*

Pseudonym	Gender	Ethnicity (UK Census Categories)	Age	Carer(s) Interviewed	City Number	Part of original forty interviews or a new interview	Number of Diary Recordings by Young Person	Total Time of Diary Recordings to Nearest Minute
Anthony	M	Black Caribbean	15	Mother	1	New	23	12 minutes
Beatrice	F	Black Caribbean	15	Mother	1	New	14	22 minutes
Clinton	M	Black Caribbean	15	Mother	2	New	7	33 minutes
Duane	M	Black Caribbean	15	Mother & Voluntary Worker	3	Original	11	13 minutes
Emmanuel	M	Black African	11	Father	3	Original	1	3 minutes
Francesca	F	Black Caribbean	15	Mother	3	New	20	11 minutes
Grant	M	Black Caribbean	15	Mother	3	New	12	20 minutes
Henry	M	Black African	12	Mother	4	New	3	2 minutes
Innocent	M	Black African	15	Voluntary Worker	4	New	6	3 minutes
Jemima	F	Black African	13	Mother	4	New	5	3 minutes