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Reported school experiences of young people living with sickle cell disorder in England

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A survey of 569 young people with sickle cell disorder (SCD) in England has found such pupils miss considerable periods of time from school, typically in short periods of two or three days. One in eight has school absences equating to government-defined 'persistent absence'. Students with SCD report that they are not helped to catch up after these school absences. Half the children reported not being allowed to use the toilet when needed and not being allowed water in class; a third reported being made to take unsuitable exercise and being called lazy when tired. Children perceived both physical environment (temperature, school furniture) and social environment (being upset by teachers or other pupils) as triggers to episodes of their illness. Policy initiatives on school absences; preventive measures to ensure maintenance of good health; and measures to prevent perceived social attitudes precipitating ill health would also support children with other chronic illnesses at school.

Introduction

In this article we report on what we believe to be the first comprehensive survey of the experiences in school of young people living with sickle cell disorder (SCD) in England. SCD is the collective name for a number of related serious inherited blood conditions, of which the most common is sickle cell anaemia. Nearly one-quarter of

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primary school pupils in England are from ethnic groups who are at higher risk of carrying genes associated with SCD, especially those of African, Caribbean, Indian, Mediterranean, Middle Eastern and Eastern European descent (Department for Education and Skills [DfES], 2006). Sickle cell disorders comprise a systemic disorder which can generate symptoms in nearly every part of the body. People with SCD may experience acute or chronic pain in any part of the body, with about a third reporting pain nearly every day, over 50% having pain on more than half of the days, and only 14% of people with SCD rarely experiencing pain (Smith *et al.*, 2008). About 10% of children with SCD undergo strokes (Steinberg, 1999). Furthermore, children with SCD may experience silent strokes, acute chest syndrome, hand-foot syndrome, leg ulcers, overwhelming infections, necrosis of the shoulders or hip joints, visual or hearing problems, headaches and jaundice, amongst many other symptoms and complications (Serjeant & Serjeant, 2001). However, and in contrast to this daunting list of potential symptoms, most children with SCD are well on most days, negotiate their lives positively, and actively seek to achieve a sense of normalcy, resenting any drawing of attention that frames them as allegedly 'different' (Atkin & Ahmad, 2000, 2001). Crucially for schools and teachers facing the myriad and complex challenges of running an education system, SCD is extremely variable in severity, both between individuals with SCD and within the same person with SCD over time. Moreover, the frequency, timing, extent and manner of physical manifestations of the medical problems associated with SCD are all liable to be different between individuals.

We begin by outlining the existing literature on young people with chronic illness at school, drawing particular attention to the potential for children with SCD to be framed within both disabling and racist discourses. We show how our questions to young people with SCD have been guided by this existing literature. We next report our methods, noting that although a hitherto hidden population, the young people did not exhibit the resistance to research that may be implied by the epithet 'hard to reach' with which some social researchers have characterised minority ethnic communities. This group of young, predominantly black, disabled children were, for the most part, keen to complete a questionnaire. Following a description of our sample, we report our findings, which include: the extent of reported school absences; the extent that children perceived they had been helped to compensate for such absences; the reported impact of the physical environment of the school on health; the role of the social environment in triggering episodes of ill health; and relative inclusion of sickle cell as an issue in the school curriculum.

Sickle cell, racism and disablement

Sickle cell disorder (SCD) is the leading 'single-gene' condition in England, affecting around 1 in every 2000 children born (NHS Sickle Cell and Thalassaemia Screening Programme, 2006). Although SCD affects children from all ethnic groups, its highest prevalence is found in children of Black African and Black Caribbean descent, children who are already faced with well-documented challenges in the education system. Moreover, it has been claimed that children with SCD live at the intersection of two

potential sources of discrimination: disabling discourses and racism, in addition to those associated, more generally, with social class and gender (Ahmad & Atkin, 1996).

Pupils living with SCD represent a particular case of children with a chronic illness within the education system. Previous research has suggested that the support offered to pupils with a chronic illness by teachers is extremely variable (Lightfoot *et al.*, 2001), even by teachers within the same school (Mukherjee *et al.*, 2000). Young people with chronic illness report that they need support from teachers in relation to absences from school, preferring not to be left to copy notes from peers, but rather valuing occasions when teachers send work home and when teachers take time to explain the work they have missed (Lightfoot *et al.*, 1999). Children with a chronic illness also state they require support in relationships with other pupils, in explaining their condition to others, and in having a person available to talk to in confidence about their health. This highlights the importance for pupils with a medical condition for teachers to be aware of and understand their chronic illness (Mukherjee *et al.*, 2000; Cunningham & Wodrich, 2006), and for good communication between health and education services (Mukherjee *et al.*, 2002). The whole school too has a role to play, in that environmental and social factors can trigger or exacerbate a chronic illness. Conversely, attention to the school environment could prevent such antecedents of illness (Ciutto *et al.*, 2006). In the case of SCD, children need to drink plenty of water to remain hydrated and help prevent sickle cell crises; to use the toilet more frequently as they cannot concentrate urine as readily; to avoid strenuous exercise, especially in inclement weather that could trigger their illness; and a recognition that the anaemia, which is an integral part of their condition, may leave them tired and lacking in concentration. Inappropriate seating arrangements, such as hard wooden science laboratory chairs, or sitting cross-legged on the floor, may also restrict the body and provoke a painful crisis. We therefore asked questions about which aspects of the physical environment of the school, such as toileting arrangements, attitudes to drinking water in class, temperature, and school furniture, provoked episodes of illness.

Although pupils with SCD do not routinely think of themselves as disabled, their social environment and attitudes of others have many features which can disable young people living with SCD (Atkin & Ahmad, 2000, 2001; Abuateya *et al.*, 2008). It has been found, for example, that children in pain feel they are not believed by teachers, who are more likely to interpret chronic pain as psychological, and less likely to respond sympathetically than if the pain were conceived of as physical in origin (Logan *et al.*, 2007). We therefore also asked questions about perceived social triggers to bouts of sickle cell illness within the school, including being upset by staff or pupils, and about reactions of staff and pupils to episodes of acute and chronic pain. We have seen, above, that SCD may be associated with impaired concentration and fatigue, but it has been pointed out that health professionals may not always be in a position to specify for teachers the educational consequences of a particular chronic illness (Thies, 1999). In our survey we asked about attitudes of teaching and physical education staff to episodes of tiredness associated with anaemia.

To date, little empirical research has been reported on the experiences of young people with SCD in schools: debates about health and health care tend to dominate.

In the USA it has been estimated that children with SCD may miss up to 30 days of schooling a year (Nettles, 1994), and this means it is important to assess the extra absences associated with SCD. Thomas and Taylor (2002) have reported that pupils with SCD state that they experience a lack of support from teachers following periods in hospital, echoing findings on chronic illness more widely that suggest there are frequently no consistent procedures in place to support a child with chronic illness in relation to missed work (Asprey & Nash, 2006). This led us to ask questions about the nature of any support following school absence and the extent to which the young person with SCD is helped to make up ground lost during that absence. Mukherjee *et al.* (2000) found that school staff reported that they needed assistance with obtaining health-related information with respect to pupils with medical needs, and it was therefore pertinent to ask whether school staff have been informed if pupils in their care have SCD. This understanding is vital because Noll *et al.* (1992) demonstrate that a lack of teacher knowledge of SCD undermines the safe care of children with SCD in school settings. Indeed, the absence of such information has led to stereotyping of such children as lacking school motivation (Noll *et al.*, 1996). Increasing teacher and peer awareness of SCD has been shown to improve school attendance and increase acceptance of SCD by school peers (Koontz *et al.*, 2004), and we therefore asked questions about how widely our respondents had shared knowledge of their condition with others. The former Inner London Education Authority (ILEA, 1989) produced guidance on responding to a child with SCD at school, guidance that included suggestions on including SCD across a wide range of school subjects in addition to biology. The UK Sickle Cell Society (2008) has produced comprehensive guidance on incorporating SCD within a range of national curriculum subjects, and this led us to pose a question in our survey to identify the range and extent of teaching about SCD in schools.

More generally, the institutional racism, which, it is claimed, characterises the experience of Black children in UK schools, has been an enduring source of debate in education research across four decades (Coard, 1971; Tomlinson, 1981; Wright, 1992; Gillborn & Mirza, 2000). However, some studies claiming to evidence racism in classroom interaction have been criticised on 'empirical, theoretical and methodological grounds' (Stevens, 2007, p. 158). Other authors have mourned a lack of attention to the interactive effects of gender and social class in assessing minority ethnic pupil school achievement (Rothon, 2008). Nonetheless, although there may have been improvements in achievement across all ethnic groups, some have claimed that the relative gap remains significant (Gillborn, 2008). At the same time, concern has grown over the number of Black students excluded from schools (Gillborn, 1998), suggesting that school absence carries different connotations for children of African and African-Caribbean descent. Black pupils start school at levels of attainment commensurate with their socio-economic peers, but comparative educational achievement erodes over time once in the education system (Demie, 2005). It is suggested that both initial teacher assessments and teacher expectations of Black pupils are of note (Gillborn, 2008). Children with SCD are vulnerable to stereotypes about commitment because of school absences (Noll *et al.*, 1996) and to being

'written off' by teachers in terms of their likely educational achievements (Darr *et al.*, 2005). They may also be subject to preconceived expectations about their physicality (Fleming, 2001), perceptions that may make it harder to appreciate a Black child with a chronic illness. This represents an important context when interpreting our findings.

Methods

The research proposal was approved by a university ethics committee and, because some recruitment took place through National Health Service (NHS) premises, by a health service Multi-Centre Research Ethics Committee, and the Research and Development Offices of six NHS Trusts. The questionnaire was developed on the basis of existing literature, and in consultation with a wide range of stakeholders, including a haematologist, a paediatrician, three specialist sickle cell counsellors who advocate for children with SCD at school as part of their role, a clinical nurse specialist, two people living with SCD, a parent, a teacher and a school nurse. It was piloted with 10 children with SCD from three different sickle cell self-help groups. No substantive changes were made to the questions as a result of the pilot. However, the age range covered was extended to include under fives where they had some experience of pre-school or nursery (because in the words of a person with SCD it may have 'already gone wrong by then'). It was also extended to include those up to 25 years old because the parent consulted pointed out that a number of people with SCD complete their education over a longer period. There was no national list of people living with SCD to form a sampling frame (although the Department of Health is currently making plans for such a register). The questionnaire was therefore administered through three routes. In each case the potential respondents were given an age-appropriate information sheet describing the research. First, 12 sickle cell voluntary groups (four in London, eight outside the capital) administered the questionnaire face to face with their members. Each of these involved a minimum of two visits to the group by researchers, the second visit including a one-hour guidance session and accompanying written guidance notes on administering the questionnaire. We received 113 responses through this route. Second, sickle cell nurse counsellors in three different primary care trusts (two in London) managed the questionnaire with their clients with SCD, yielding 56 responses. Third, one of the research team (HA) attended sickle cell outpatient clinics in three London NHS hospital trusts 44 times in total within a one-year period. Those young people who agreed to take part in the study were referred to the researcher by the consultants or nurses. In these cases the young person was assisted by the researcher to complete the questionnaire. This route produced 400 responses. The onerous demands of NHS research governance (see Dingwall, 2006; Dixon-Woods *et al.*, 2007) in which obtaining all necessary permissions can take over a year, made it imperative to focus on the larger clinics in London, where an estimated three-quarters of all children with SCD reside. Because of the lack of a sampling frame and the multifocal nature of the survey we do not have a response

rate, but only five potential respondents were noted to have declined directly to complete a questionnaire.

School experience for young people with SCD: a preliminary mapping

We received 571 completed questionnaires. Two were excluded (one where the person was a carrier, not someone with SCD itself; and one where the person had a serious inherited blood disorder that was not sickle cell), leaving 569 valid responses. Based on an approximation of 12,500 people living with SCD in England (Streetly, 2007), an assumed average life expectancy of 55 years (a midpoint of the 45–64 years for different types of SCD given by Zeuner *et al.*, 1999, p. 76), and our effective age range for recruitment of 4–25 year-olds, we estimate that there would be 5000 people with SCD within that age range in England. We therefore estimate that we have responses from around a 10% sample of all young people living with SCD in England. The age, gender and ethnic breakdown of responses is given in Tables 1 and 2.

SCD is not a sex-related genetic condition so any gender differences in replies would have reflected a differential attendance at routine medical clinics, which was the main source of respondents and/or a differential willingness to respond to the research. The age range reflects the fact that our recruitment strategy at hospital clinics, which accounted for 70% of the overall recruitment, was focused to a greater degree on paediatric rather than on adult clinics. The high proportion of Black African respondents is a product of the much higher prevalence of SCD in people of more recent African descent (25% carriers, 2% living with SCD), as opposed to Black Caribbean communities (10% carriers, 0.25% living with SCD). It might also reflect the make-up of London clinics, which helped generate a substantial proportion (70%) of the sample, as they are more likely to have people of African origin than those operating outside London.

Table 1. Characteristics of the sample of young people with SCD

	Number	Valid %
Gender		
Female	288	50.6
Male	281	49.4
Total	569	100.0
Age		
4	16	2.8
5–10	243	42.9
11–18	276	48.7
19–25	32	5.6
Missing values	2	—
Total	569	100.0

Table 2. Ethnicity of the sample of young people with SCD

	Number	%
Black African (Angolan)	21	3.7
Black African (Congolese)	19	3.3
Black African (Ghanaian)	62	10.9
Black African (Nigerian)	183	32.2
Black African (Sierra Leonean)	46	8.1
Black African (Sudanese)	6	1.1
Black African (Somali)	6	1.1
Black Caribbean	162	28.5
Black Other	46	8.1
Indian	2	0.4
Other Asian	3	0.6
White English/Scottish/Welsh	3	0.6
Other White	1	0.2
Any Other	2	0.4
Missing	7	1.2
Total	569	100.0

School absence and the institutional response

The children with SCD recorded that they missed an average of 16.3 days (equivalent to 8.4% of school a year) because of illness specifically associated with their sickle cell, in addition to days lost for other illnesses or other reasons (Table 3). However, this mean figure hides a wide variation, with 11.8% citing no days lost, but conversely, 31.2% quoting an absence of 15 days or more, and 12.3% reporting school absences of 32 days or more. In a few cases this number was higher still, and in two cases the young person claimed that they had missed 200 days of school, in other words almost all of the school year. However, the most frequently reported periods of time absent from school for each absence were two days (11.2% of valid responses), three days (12.7%) or five days (11.9%). It seems that a great deal of school can be missed, but that the total amount lost may vary greatly. For the most part, the days lost in any one period of absence appears to be five days or less and most frequently just a couple of days.

Table 3. Number of reported days absent from school owing to sickle cell

	Total days missed	Consecutive days missed
Mean	16.27	7.14
Median	9	4
Mode	10	3
Range	0–200	0–180
Standard deviation	25.39	12.04

Table 4. When lessons missed how much do children with sickle cell perceive that they are helped to catch up?

	Number	Valid %
Not helped to catch up at all (0% of the way)	100	18.6
Helped to catch up 1–25% of the way	170	31.7
Helped to catch up 26–50% of the way	166	30.9
Helped to catch up 51–75% of the way	68	12.7
Helped to catch up 76–99% of the way	3	0.6
Helped to catch up all the way (100% of the way)	30	5.6
Missing values	32	—
Mean (treating ordinal level data as if it were interval)	38% of the way	

The young people were also asked to comment on how much they felt they were helped by the school to 'catch up', placing themselves somewhere on a scale between 0% (not helped to catch up at all) through to 100% (helped to catch up completely). As Table 4 shows, a small minority, around 5%, thought they had been helped to catch up completely. Over four-fifths felt they had been helped to catch up half, or less than half, of what they had missed through illness. Over 90% thought they had not been helped to fully catch up. Around one in six (18.6%) thought they had not been helped to catch up lessons they had missed at all.

We then asked children what their experiences had been with regard to other issues at school. Each of these issues represents a key preventive measure and/or a significant side-effect of sickle cell anaemia. For example, it is important for a child with SCD to be allowed to drink water in class, as this is important for keeping well hydrated and preventing the most common symptom, the acute vaso-occlusive or painful crisis, in which blood capillaries become blocked, associated with mild, moderate or excruciating pain in the part of the body concerned. Approaching half of our respondents (45.8% valid responses) claimed to have been prevented from taking a drink (Table 5). It is also vital that children with SCD are allowed to go to the toilet when needed, as children with sickle cell cannot concentrate urine as readily as normal, so need to pass urine more frequently. Nearly three in every five of the pupils with SCD claimed that they had been prevented from going to the toilet when needed. Sickle cell painful crises can also be precipitated by exposure to weather conditions likely to rapidly cool the skin temperature (Jones *et al.*, 2005). Swimming

Table 5. How do children with sickle cell claim they are treated at school?

Reported experience at school	Number	Valid %
Prevented from taking a drink in class	260	45.8
Prevented from going to the toilet	326	57.4
Made to do exercise that was unsuitable	206	36.3
Called lazy when feeling tired	192	33.8

in unheated outdoor pools can reproduce these deleterious environmental conditions. So too can outdoor exercise in windy and rainy conditions (for example, cross-country runs in the cold rain could precipitate a sickle cell painful crisis). Furthermore, strenuous exercise, especially 'heroic' exercise or exercise-to-exhaustion is not recommended for people with SCD. Over a third of young people stated they had been compelled to undertake exercise they regarded as unsuitable for someone living with SCD. Finally, children with SCD have a form of anaemia that may leave them tired and unable to concentrate. One-third of our sample reported that they had been labelled 'lazy' when they felt they were tired from the anaemia.

We also asked about what factors, if any, had triggered a sickle cell crisis when at school. In terms of the physical environment, over half of all respondents (53.6% of valid responses) reported that the temperature of the school (either too hot or too cold) had provoked a sickle cell crisis (Table 6). Approximately one-fifth (21.2%) reported that the school furniture had caused a sickle cell crisis. Examples included hard-edged wooden stools characteristic of science laboratory furniture, and at primary school being asked to sit cross-legged for sustained periods of time. In terms of the social environment, just under one-third had perceived that their crisis had been triggered by becoming upset by the actions of a teacher (30.5%) and about a quarter (24.5%) by the behaviour of another pupil.

A large majority (79.3%) of the young people with SCD reported that they had experienced sickle cell-related pain whilst at school. Around three-quarters suggested that they related this information to the teacher, implying some pupils managed their pain without informing the teacher (Table 7). Not all others around them were reported to believe the child was in pain. About three-fifths of teachers and about half of other pupils were perceived by the young person as believing that they were in pain. Just under half of the teachers were reported to give help to the child in pain and one in four children recounted being given painkilling drugs at the school. In one in five cases the children were sent to hospital and in three in five cases the child was collected from school and taken home.

A number of voluntary groups for children with chronic illnesses promote teaching about their particular chronic illness within the school curriculum (National Society for Epilepsy, 2005; Asthma UK, 2008). The main UK support group, the Sickle Cell Society, has also promoted the idea that sickle cell could be taught not only as part of the formal science curriculum, but also in addressing other subjects within the various

Table 6. What do children with sickle cell report starts a painful crisis at school?

Reported trigger for a sickle cell crisis	Number	Valid %
Made to undertake unsuitable exercise	243	43.2
School was too hot or too cold	302	53.6
Being upset by a teacher	170	30.2
Being upset by a pupil	139	24.7
The school furniture	120	21.3

Table 7. What is reported to happen when a child has sickle cell-related pain at school?

Reported reactions of others to the pain associated with sickle cell disorders	Number	Valid %
Young person tells the teacher they are in pain	422	74.8
Teacher is reported to believe the person is in pain	352	62.4
Children are reported to believe the person is in pain	300	53.2
Teacher is reported to help the child in pain	267	47.3
Child is given painkillers in school	154	27.3
Child is sent to hospital	111	19.7
Child is collected from school by parent/carer	334	59.2

Table 8. In which school subjects do the children with SCD report being taught about SCD?

	Number	Valid %
Biology or Science	128	22.6
Maths	18	3.2
English	19	3.4
History	13	2.3
Geography	15	2.7
Physical Education or Sports	36	6.4
Personal, Social and Health Education	50	8.8
Art, Dance or Drama	20	3.5
Assembly	62	11.0
Other subjects	41	7.2

key stages of the national curriculum. About a fifth of young people said that they had received tuition about sickle cell as part of biology or science lessons, and about 10% that the issue had been covered in each of school assembly and personal, health and social education respectively (Table 8). Small numbers of children, generally less than 5%, claimed that they had been taught about SCD in other lessons.

Discussion

The ethnic profile of the respondent population suggests that the complex patterns of migration to the UK during the 1990s and 2000s have changed the size and ethnic composition of England's Black communities in such a way as to make SCD an increasingly important issue for education policy. England's Black African population has much higher rates of SCD compared to the Black Caribbean or Black Other groups. This importance is likely to increase substantially over the next 20 years as differential fertility, population age structure and possible future migration are all likely to increase the number of children with SCD resident in England. The degree

to which the changing profile within England's overall Black communities makes a difference to demands on services is only slowly being realised by commissioners of health services (Dyson *et al.*, 2007), and, as yet, does not seem to have impacted at all on planning by children and young people's education services (Dyson *et al.*, 2008)

The average number of days children with SCD in England reported missing school owing to sickle cell-related illness (16.3 days, 32.6 sessions) is considerably less than the 30 days reported for African-American children with SCD in the USA (Nettles, 1994), though the latter may refer to total absences. Possible other reasons for this difference include a different socio-economic profile of the African-American, British African-Caribbean and British African populations affected by SCD, and differences in the health systems (in the USA, treatment for prevention of initial or subsequent strokes only became possible under Medicaid with the 2004 Sickle Cell Treatment Act) resulting in differing levels of accessible health care and preventive treatment. The figure for sickle cell-related absence alone equates to 8.4% of possible school attendance and is approximately double the national average of 3.47% of total time lost owing to all illness (Department for Children, Schools and Families [DCSF], 2008). The average total from sickle cell-related illness alone exceeds total overall absence for Black children (African, Caribbean and Other combined) for the leading 20 local authority areas from whom our sample was drawn, figures which range from 3.55% to 7.55% (DCSF, 2008). It is also approximately double the eight days per year cited for children with diabetes (Cowan *et al.*, 1997) or the 7.6 days for children with asthma (McPherson *et al.*, 2006). However, the latter study shows that it is important not to treat any measured level as a natural or inevitable consequence of chronic illness, and McPherson and colleagues reduced asthma absences to 5.4 days with an educational intervention. As we have seen, Koontz *et al.* (2004) increased inclusion of pupils with SCD in the USA by means of a substantial educational intervention increasing specific knowledge of SCD among teachers and school peers.

In our sample, around one in eight young people with SCD (12.3%) record that they miss an amount of schooling associated with their SCD alone that meets the threshold for the DCSF's definition of 'persistence absence' (DCSF, 2008). Furthermore, 31.2% cited an absence of 15 days or more. Guidance issued by the forerunner of the DCSF in 2002 reminds local authorities and schools in England that they have a responsibility under section 19 of the Education Act 1996 to make arrangements for children who by virtue of illness 'may not for any period receive suitable education unless such arrangements are made for them' (DfES, 2002, p. 2). Since the legal requirement for schools is to initiate provision when a threshold of 15 days have been missed (DCSF, 2007), one would expect systems to have been initiated to support such students to catch up lessons missed. This applies irrespective of whether or not the school has specifically been told that the child has SCD, since any absences of this magnitude ought to give educators cause for concern. However, young people with SCD overwhelmingly perceive that they have been failed in being helped to make up schooling missed through illness. The episodic pattern of the days missed suggests that support mechanisms would need to be attuned to such patterns. Although official

guidance does mention 'prolonged *or recurring* periods of absence from school' (DfES, 2002, p. 2, our emphasis), the remainder of the guidance document concentrates on pupils 'without access to education for more than 15 working days' and focuses remedial action on hospital and/or home tuition. Although it may be the intention of the guidance to include recurrent short absences within its scope, the phrasing and context of the remainder of the guidance, and the likelihood that schools hard pressed for resources will interpret the 15 days narrowly as implying consecutive days, means that in practice, as Darr *et al.* (2005) found, the administrative time required to initiate home teaching is not commensurate with short recurrent absences, leaving pupils with SCD unsupported. In this respect children with SCD would benefit from a systematic implementation of the principles for supporting children with medical needs outlined by Farrell and Harris (2003), which stress continued ownership of the child's education by the mainstream school; good partnership working; flexibility; and responsiveness and clarity in roles, responsibilities and procedures.

To the extent that the reported experiences reflect the reality on the ground, then the figures reported in Table 5 underscore the challenging nature of the school experience for a child living with SCD. Whilst these remain *reported* experiences, several contextual factors suggest they may have a basis in reality. The findings confirm the situation in the USA (Koontz *et al.*, 2004). A national survey of local authorities has suggested few education authorities have addressed sickle cell as an issue (Dyson *et al.*, 2008), suggesting educational institutions struggle to engage with the experiences of children with SCD. Moreover the sheer numbers claiming the experiences cited means that it is unlikely the accounts can all be put down to exaggeration.

There are several possible factors that may explain some of the findings of this study. It is possible that substantial numbers of parents and pupils do not disclose their SCD to school or teachers, and this may explain some of the results cited.[1] It is also possible that schools do not appreciate the potential severity of SCD, which would not be surprising given the long struggle over decades to persuade health professionals to take the symptoms of SCD seriously (see Anionwu & Atkin, 2001). It could be that schools have clinical information but do not appreciate the educational implications of this information (Thies, 1999) or are unable to act effectively on that information for reasons unknown. Further investigation, currently being undertaken by the authors, is needed to establish the impact of these or other factors.

The ability of schools to respond appropriately to children with SCD may be limited by the scope of the current generic guidance on chronic illness and education. The emphasis in policy documents is on reactive measures (DfES, 2002) and on the administration of medicines and creation of care plans (DfES, 2005). Even within those parts of official guidance concerned with establishing individual care plans for children with medical needs, the importance of *preventive measures* by attention to the physical environment is not made explicit. For example, about half of children with SCD claim that they have at some point been prevented from taking a drink in class, a measure that would enable them to keep up their level of hydration and prevent the onset of a painful sickle cell crisis. Identifying appropriate preventive measures for children with SCD could readily be broadened to an environmental audit of the

school to eliminate potential triggers for a wide range of chronic illnesses, and such an initiative could therefore help children with medical conditions such as asthma and epilepsy as well. Second, chronic illness is above all a *social* experience (Bury, 1991; Williams, 1999) and the physical experience of living with a chronic illness is thus always mediated though prevailing social attitudes and institutional arrangements. Substantial proportions of pupils living with SCD (variously between a quarter and a half) claim to have experienced reactions of others (being upset by a teacher or pupil; being made to take unsuitable exercise; being called lazy and so on) that in themselves seem to have made the experience of SCD at school worse, and in many cases are said to be associated with subsequent physical symptoms of SCD, including sickle cell painful crises. Schools could initiate an environmental audit for SCD, covering such issues as hydration, toilet breaks, school furniture, school temperature and the like, and develop policies on how to support pupils with SCD in respect of these factors without simultaneously constructing them as different.

Where the pain of children with SCD is believed and taken seriously, the emphasis understandably appears to be on obtaining appropriate medical help for the child as quickly as possible by sending them to hospital. Whilst this is entirely appropriate where the pain is severe and intractable, or when the child is showing signs and symptoms of a stroke, young people with SCD are frequently able to manage their pain without admission to hospital (Atkin & Ahmad, 2000). Given the emphasis on school inclusion and ensuring that 'every child matters' in government guidelines (DfES, 2004a, b; DfES & Department of Health, 2004) it would seem appropriate for schools to develop ways of keeping the child within school in instances where the symptoms are mild or moderate. This could be achieved through having a space dedicated for time out and a rest, leaving open the possibility of returning to lessons later in the day. However, teachers may not feel competent to be able to judge severity, and, in the current litigious climate, the risk might be considered too great. Moreover, not all schools may have access to sick bay-type spaces, and in any case may not have the staff to supervise such spaces. The finding that a quarter of children with SCD who experience pain report being administered painkilling drugs at school, but the remainder do not, suggests a need to find out why some schools are able to incorporate such procedures for a child with SCD and others are not. Both in terms of space for sick bays and administration of medicines, the availability of a school nurse would seem to be a key resource for children living with a chronic illness in school.

The potential for SCD to be addressed within a range of curriculum subjects does not appear to be widely exercised. However, the fact that, according to replies to the questionnaire, there are a few cases for each subject where SCD is apparently incorporated into the curriculum, suggests that there are some isolated examples of good practice that could be built upon. There are many policy frameworks to justify and encourage such good practice, ranging from disability discrimination, race relations and health and safety frameworks as well as individual health care plans (DfES, 2002). However, few educational institutions seem to realize the potential implications of adapting current policy initiatives to improve the experience of those affected by SCD.

Conclusion

A first national survey of children with SCD at school in England has revealed a substantial population of children with a chronic illness who, hitherto, have received little attention in terms of policy making. Children with SCD report how they miss variable but in some cases substantial periods of schooling. These periods of absence are often at levels that, under current legislation and guidance, should trigger special initiatives from schools to support children in making up lessons missed. In around one in eight cases, these levels of school absenteeism are at levels implicitly deemed socially unacceptable by the definition of 'persistent absenteeism'. Whatever systems may or may not be currently in place to support children with SCD in making the most of their schooling in the light of such absences, these measures are perceived to be failing. Young people with SCD report that, on average, they are helped to catch up only around a third of what they feel they have missed. The majority perceive they are not helped to make up half of the schooling missed, and one in six report that they are not effectively helped to catch up *any* of their missed schooling. The episodic nature of much of the missed schooling, in which the most frequently reported absences are between two and five days at a time, may help explain both why the issue seems to have remained relatively hidden, and why current structures may struggle to deal adequately with the challenge.

Current guidance on the management of children with chronic illness in school seems to fail children with SCD in a number of important respects. The relevant documentation does not fully address preventive measures in the case of chronic illness, nor consider that children living with a chronic illness may be embodied in gendered and racialised ways, nor that the child, their condition and the physical and social environment of the school may interact in complex ways. In summary, SCD is a currently hidden, but increasing, part of the range of chronic illnesses met by teachers at school in England. Current frameworks, be this in responding appropriately to school absences, in avoiding environmental or social triggers to ill health, or in making the curriculum relevant to the experiences of minority ethnic children, do not appear to be supporting the inclusion of children with SCD in schools in England. However, attending to the physical and social needs of children living with SCD would not only help those children but could provide important lessons in how to adequately respond to children with a wide range of chronic illnesses in the school system.

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Note

1. These issues are extremely complex and the authors intend to investigate the data further in subsequent analyses.

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