

Research paper

School ethos and variation in health experience of young people with sickle cell disorder at school

Sue E Dyson RN RM BSc MSc EdD

Reader in Nurse Education, School of Nursing and Midwifery, Edith Murphy Building, De Montfort University, Leicester, UK

Karl Atkin BA DPhil

Professor, Department of Health Sciences, University of York, York, UK

Lorraine Culley BA MA PhD

Professor of Social Sciences in Health, School of Applied Social Sciences, De Montfort University, Leicester, UK

Jack Demaine BA PhD

Senior Lecturer in Social Policy, Department of Social Sciences, Loughborough University, Loughborough, UK

Simon M Dyson BSc (Soc) MPhil PhD

Professor of Applied Sociology, Unit for the Social Study of Thalassaemia and Sickle Cell, De Montfort University, Leicester, UK

What is known on this subject

- In multi-ethnic societies such as the UK, sickle cell disorder (SCD) is found at higher rates in minority ethnic groups that are already marginalised and underserved in terms of health and social care.
- Young people with SCD report high levels of negative experiences at school that have an adverse impact on their health and affect both their school attendance and attainment.
- Disclosure of sickle cell status is not associated with improvement in health-related experiences at school, and alternative explanations for variable health experiences at school are required.

What this paper adds

- Young people with chronic illnesses such as SCD spend a substantial proportion of their lives in school settings, and school experience is therefore an important determinant of their overall health and well-being.
- School ethos is a plausible mediator of school experiences affecting the health of young people with SCD in schools.
- Health protection of young people with SCD should address factors such as the attitudes expected of teachers and other young people, how young people relate to each other and to staff, how the school relates to the community in which it is situated, and how the school ensures the spiritual, moral, cultural and social development of young people.

ABSTRACT

Young people with serious chronic illnesses, such as sickle cell disorder, report high levels of negative experiences at school that have adverse effects on their health. Disclosure of sickle cell status appears to be unrelated to improved experiences, and alternative explanations for variable health experiences at school are required. This paper draws on a multi-methods study of young people with sickle cell disorder in England in an attempt to make sense of variable experiences unrelated to disease severity or to teacher/peer awareness of sickle cell disorder. School ethos refers to the manner in which school-based interactions combine to bring into effect school values, including the attitudes expected of

young people, the attitudes expected of teachers, how young people relate to each other, how young people relate to staff, how the school relates to the community, and a holistic concern with the spiritual, moral, cultural and social development of the young person. It is proposed that these interactions and resulting values are a key to understanding the variable health experiences of young people with sickle cell disorder at school.

Keywords: chronic disease, health literacy, organisational culture, school health, sickle cell, young children

Introduction

Sickle cell disorder (SCD) is a serious inherited chronic illness that affects all ethnic groups, but which in the UK is most prevalent in people of black African and black Caribbean descent (Streetly *et al*, 2010). To date, the experience of young people with SCD is under-researched within both health and education policy (Atkin and Anionwu, 2010). The experience of illness within education arenas is an especially under-researched area, given that children and young people spend such a high proportion of their time negotiating such settings as part of managing their long-term health condition. Young people with SCD report negative school events that trigger or worsen their illness experience. Sharing knowledge of sickle cell status with either teachers or school peers does not improve their physical, mental and social health experiences at school (Dyson *et al*, 2010a). This leads us to consider that less tangible aspects of the school context may constitute a plausible explanation of the varied health experiences of young people with SCD in schools in England. In this paper we outline SCD, review some of the key ideas about *school climate*, *school culture* and *school ethos*, and consider the application of school ethos to empirical data drawn from a multi-methods research programme to investigate the experiences of young people with SCD at school.

Background

Young people with SCD exhibit diverse health needs at school because of the variable nature of the condition and the variation in the social reactions of others, both

teachers and peers. People with SCD are susceptible to episodes of acute and chronic pain and to severe anaemia. Such episodes may be exacerbated by extremes of heat, cold, dehydration, stress or strenuous activity. These can also adversely affect the person's ability to concentrate and to engage in learning activities. With this in mind, schools need to respond to the educational needs of young people whose learning may be compromised. Schools have a responsibility to provide a learning environment that is integrally responsive to all young people. As such, schools need to foster an ethos, a way of thinking and being, that values human rights, diversity and equity, and ultimately facilitates successful learning for all members of the school community (Johnson, 2003).

A positive school ethos, characterised by student and teacher cohesion, positive teacher attitudes towards young people, an emphasis on positive rewards, and consistent and shared values and standards is pivotal in shaping school experience (Rutter *et al*, 1979). A positive school ethos can facilitate the kind of learning environment that is essential for young people with long-standing chronic conditions such as SCD if they are to reach their potential. A negative school ethos, or one that does not recognise consistent and shared values and standards, and does not value the participation of young people and parents in school life, may prove to be a barrier to effective learning for young people with chronic illnesses such as SCD. Changes to school policy and practice may be regarded by some schools as counterproductive, serving to prioritise the rights of some young people over others. However, young people with SCD face health challenges that are physical (dehydration, pain and anaemia), mental (stress associated with taunting, bullying or body image) and social (isolation, especially in relation to school re-entry after absence, exclusion from school

activities, and being perceived as different from peers). Teachers should respect the rights of young people to have their physical needs met while at the same time ensuring their mental well-being by maintaining dignity and privacy. When respecting young people's rights to protection of their physical health, schools need to be careful not to draw attention to individuals in ways that differentiate them from their peer group and undermine their social health.

To more fully understand the reported school experiences of young people with SCD in our study, in particular why the decision to either disclose or not disclose their SCD to a range of significant others does not appear to be correlated with school experience, we needed to look beyond mere reporting of health status. We consider the concepts of *school climate*, *culture* and *ethos*, terms that are distinct but that are often used interchangeably (Glover and Coleman, 2005), and draw attention to limitations of ostensibly similar concepts such as *health-promoting schools* and *health literacy*, before looking in detail at *school ethos* to explain the reported school experiences of young people with SCD.

School climate, culture and ethos

School climate is defined by Moos (1979) as the social atmosphere of the learning environment in which young people have different experiences according to the protocols set up by teachers and administration. It is a term often used to describe the school environment in the North American and Australian context. It appears to refer to the relationship that young people have with the school as an organisation, with its attendant rules and procedures, as well as their relationships with teachers and with each other. In the UK and Europe the term *culture* tends to be used. The term *school climate* is used when objective data are under consideration, whereas *school ethos* is used when more subjective descriptors are involved (Glover and

Coleman, 2005). *Culture*, on the other hand, is used when *ethos* and *climate* are brought together as an integrative force in investigation or debate. In this context, *culture* refers to indicators that are measurable yet also capable of subjective evaluation (Glover and Coleman, 2005). Culture is viewed, therefore, as an amalgam of the *way* things are done, reconciled with descriptors of *how* things are done, and is arguably a more complex and dynamic set of relationships within the school environment than is covered by either climate or ethos (Bolman and Deal, 1984; Peterson and Deal, 1998) (see Box 1).

Ethos appears in all contexts as a descriptor of social dynamics either in place or as a broad component of the term *culture*. Ethos, unlike climate, is less concerned with the measurement of environmental factors and outcomes for young people, and is more concerned with the way in which people interact in developing and then attaining a set of values (Glover and Coleman, 2005). Ethos has been viewed from both positivist and anti-positivist perspectives (Donnelly, 2000). From a positivist perspective, it is a top-down prescription of social reality, an objective phenomenon, and exists independently of the people and social events in an organisation. *School ethos* in this sense would necessarily require the authorities within the organisation to commit to the types of behaviour expected throughout the school, formally expressed in the school's aims and objectives. An anti-positivist view of school ethos is seen as less formal, being more to do with social interaction and processes emanating from individual and group interaction. In this sense, *school ethos* need not be stated or documented in any formal way, being more akin to the concept of *culture*, which emerges from social interaction and is part of, not independent of, the organisation and its members (Donnelly, 2000). Irrespective of philosophical position, the notion of school ethos has, since Rutter *et al* (1979) published their findings, become firmly associated with school effectiveness and improvement (Smith, 2003). This preoccupation with school effectiveness and improvement and subsequent target setting may lead schools to formally espouse a particular ethos on the one hand, while on the other

Box 1 Less tangible aspects of the school as an organisation

School climate	Refers to objective input and output measures, such as the relationships of young people to school rules, policies and procedures
School ethos	Refers to more subjective aspects, such as the ways in which young people and teachers relate to other pupils and teachers, and how this interaction constructs school values on the ground
School culture	Refers to how school climate and school ethos come together to create the overall learning environment

engaging in interactional practices that negate the official message. For example, schools that are pre-occupied with attainment may fail to respond to the individual health and learning needs of the young person.

The holistic emphasis of school climate, ethos or environment has superficial parallels with concepts such as the *health-promoting school* (Lee, 2009), but although such concepts may end with recommendations to adjust the school environment, the starting point seems to be the health and lifestyle behaviours of the general school population (McLellan *et al* 1999), rather than consideration of specific reasonable adjustments to support the health and learning of a young person living with a chronic condition such as SCD. Moreover, the irony is that an ostensibly collectivist framework remains individualistic in its conception of the mechanisms through which differential health statuses are effected, and outwith the social determinants of health such as material deprivation and racism (Karlsen and Nazroo, 2002; Williams *et al*, 2003). Furthermore, related concepts such as *health literacy* reinforce this individualising of social problems (Paasche-Orlow and Wolf, 2010), and ignore the fact that at least part of the social reproduction of racism may itself be through the workings of the educational system (Gillborn, 2008), and that for a young person living with chronic illness at school, a strong *health literacy* may itself be in tension with the procedures of a school (Dyson *et al*, 2011).

In summary, *school climate* concerns the measurable input and outcome features of the school experience, whereas *ethos* is concerned with the subjective values and principles underpinning policy and practice. *Culture* is said to integrate the environmental, organisational and experiential features of school existence to offer a context for teaching and learning, and its subsequent improvement. In the absence of data relating to overall school aims and objectives, we are reliant in this study on the reported and therefore subjective accounts given by the young people with SCD and their carers. We have therefore chosen to frame our discussion within the concept of *school ethos*, rather than *climate* or *culture*, as, of the three, this is the concept commensurate with the subjective reported accounts that form the basis of our investigation of school experience.

The study

Design

The overall aim of the research programme was to provide an understanding of the experiences of young people with SCD at school. Within this overall aim,

the purpose of this paper was to provide a plausible explanation of variation in school experience, when evidence suggests that SCD disclosure to teachers is not associated with reported improvement in experience. A mixed methods approach was selected to facilitate collection of a range of data from a variety of sources. The first of these was a questionnaire developed to ascertain the experiences of young people at school, asking about school absence, support provided, and whether their SCD status was disclosed to teachers and/or other young people. Secondly, tape-recorded 1-hour interviews, in the form of 'guided conversations' (Fielding, 1993, p. 144), also asked about experiences at school that could improve or worsen their symptoms, and focused further on reasons for and against disclosing SCD status to teachers and/or peers. Thirdly, case studies were conducted with 10 young people, selected for diversity in terms of gender and ethnicity, and encompassing a 1-hour tape-recorded interview with the young person, a 1-hour recorded interview with their main carer, and a 2-week diary of their school experiences, captured by speaking about their experiences into a digital recorder at the end of the school day. The case studies covered all of the issues mentioned above, but also asked the carers about perceived racism. The diaries also elicited, without specific questioning of the young people, accounts of bullying at school.

Ethical issues

The study was approved by De Montfort University Human Research Ethics Committee, a multi-centre health services (NHS) ethics committee and six health services research and development offices in different English localities. In each case potential respondents were offered age-appropriate information sheets. Completion and return of questionnaires was assumed to imply consent. Those invited to take part in interviews and case studies were asked for their signed written assent (if under 16 years of age) and the written consent of their carers. Those who were older were able to give their own consent.

Participants and data collected from questionnaires

Young people with SCD aged 4–25 years were recruited from three London outpatient clinics, three primary care settings (London and Birmingham) and 12 local sickle cell support groups (covering London, the South West, the West Midlands and the East Midlands). There were equal numbers of male and female participants. Although our recruitment age range was 4–25 years, the majority of the respondents were within the age range for compulsory schooling in

England (5–16 years). SCD can affect any ethnic group, but the largest groups in our sample were young black people of either African or Caribbean descent (Dyson *et al*, 2010b), reflecting the current prevalence of SCD in different socially defined ethnic groups (Streetly *et al*, 2010). A total of 569 questionnaires, administered face to face, were completed by the young people or their main carers. Only five potential respondents declined to complete a questionnaire. Data were entered and analysed using SPSS 16.0 (Dyson *et al*, 2010a).

Participants and data collected from interviews

A total of 40 audio-recorded interviews were conducted with young people aged 6–25 years (average age 16 years). There were 21 female and 19 male participants, and 24 black Africans, 15 black Caribbeans and one British Asian, purposively selected to reflect diversity in both level of school attainment and level of perceived school support. The interviews were transcribed in full and analysed using a broadly thematic approach within a Bourdieusian theoretical framework (Dyson *et al*, 2011).

Participants and data collection from case studies

A total of 10 case studies were conducted with male and female participants of both black African and black Caribbean descent. These consisted of taped interviews with the 10 young people with SCD, interviews with their main carer, and 2-week diaries kept by the young people with SCD. These were analysed by grouping young person interviews, carer interviews and diaries covering the same 'case' together, and identifying recurrent themes in the data.

Field notes were also kept by the research team on events and informal meetings. We draw on all of these sources of data in presenting our arguments in this paper.

Findings

Young people with SCD faced challenges to their physical health at school. These reported negative experiences included being prevented from using the toilet (people with SCD cannot concentrate their urine and need to pass dilute urine frequently), being denied access to water (remaining hydrated is a key measure in the prevention of illness), being compelled to take strenuous exercise (triggering episodes of ill health) and being labelled as 'lazy' by teachers

(ongoing severe anaemia in SCD leads to tiredness, lethargy and lack of concentration). There was no statistical association between the extent of reported disclosure of the participants' sickle cell status to school staff and reported exposure to these health-damaging events at school. Equally there was no statistical link between declaring their SCD status to school peers and reporting having had these negative experiences (Dyson *et al*, 2010a). Positive and negative experiences were equally in evidence when teachers and classmates knew and when they did not know that the young person had SCD. The severity of the SCD symptoms did not appear to explain levels of exposure to negative responses in school. We therefore need to look beyond the apparently plausible, but actually incorrect, notion that school experiences can be improved by informing teachers and peers that the young person has SCD. The possible explanation that we put forward here is school ethos.

School ethos and the reported experiences of young people with SCD

As we have seen, the ethos of an institution is generally taken to refer to the distinguishing character, beliefs and moral nature of the organisation concerned. Thus *school ethos* has to do with the spirit or fundamental values of a school. In the UK, the government ministry provided guidance to schools encouraging them to think about their school ethos, and suggested areas of concern that might inform such an ethos (Department for Children, Schools and Families, 2010). These indicators include the attitudes expected of young people and teachers, how young people relate to each other and to staff, how the school relates to the community in which it is situated, and how the school ensures the spiritual, moral, cultural and social development of the young people attending the school. We shall look at each of these areas in turn.

Attitudes expected of young people

If we take as a starting point the issue of the attitudes expected of young people, we can see that a school ethos cannot simply be a case of attending to these factors in isolation. For example, one might argue that a positive school ethos will attempt to inculcate good behaviours (e.g. to attend school regularly, to be attentive, not to be disruptive, and to push oneself to one's limits). However, people with SCD may miss considerable amounts of schooling and so not attend regularly. Their anaemia may leave them feeling tired, unable to concentrate, and vulnerable to the charge of

being 'lazy.' They may want to take care when exercising and resist attempts to push themselves. Requests for water or for toilet breaks may be interpreted as disruptive of classroom routines, as the following young person suggests:

'... whenever I needed to go toilet I couldn't. So yeah that is when I said that if I wet myself she would dry clean it, she would pay for the dry cleaning. She was being ridiculous, I told her. ... The next time I asked she was like 'No wet yourself.' I didn't actually wet myself but I was so close one time, so I just walked out. ... When I needed to go toilet I would say, I would ask, can I go toilet please? She would say no, so I would ask again. Can I go toilet please? No. Third time I am going toilet now, get my stuff go toilet, come back and sit down. She was like '(name), here, now' and have a go at me, then my mum went to see the head teacher, it is like so uncalled for.'

(Interview 10, black African female, 18 years of age)

It could be argued that a school can only be said to have a positive ethos if that ethos is holistic and informs all aspects of school life. If it is reduced to a programmatic or mechanistic application of procedures that take no account of, or do not make reasonable adjustments for, young people with long-term health problems or disability, the young person with SCD is positioned as deviant, transgressing school values. The Equality Act 2010 permits a school to undertake positive action provisions that entail allowing schools to develop measures that are designed to alleviate disadvantages experienced by, or to meet the particular needs of, young people with particular protected characteristics. This could, for example, include those living with SCD.

Attitudes expected of teachers

One key aspect of enabling young people to be high achievers in gaining educational qualifications is the extent to which teachers do not limit their expectations of young people from low-income backgrounds or young black people with regard to achievement. This could plausibly be the case from either end of the political spectrum, that is, a racist belief in genetic or cultural inadequacies of certain categories of young people, or a belief in the enduring capacity of poverty and racism to erode educational performance. A positive school ethos is arguably one that does not place limits on expectations, and instead expects high standards from its young people. Even in mixed-ability groups this could take the form of an institutional commitment that all young people will leave the school with at least one publicly recognised qualification. A poor school ethos would be one in which teachers make assumptions about the abilities and potential of certain young people and restrict their opportunities in ways that could become self-fulfilling.

For example, one young person in our study gave the following account of the effects of anaemia on her learning, and the teachers' expectations of her:

'Right, teachers some of them are understanding because they [think that] I would do the work if I could, but they understand that I do get tired. Some teachers will think I'm lazy, and I'm thinking if you give me the work, I'll take it home and do it when I can, when I [have] a burst of energy, but some teachers really think I'm lazy, and that like, I'm not, like/I'll get the grades for you, but they think I'm lazy, so they're like, 'How do you/Are you cheating duhduh', and like I *do* know the material, I get tired so I won't like get notes from someone else, or something like that just to keep up with the rest of the class.'

(Interview 1, black African female, 16 years of age)

The attitude of the teacher in this account is to suggest that the young person with SCD has limited ability, such that success in school work is attributed to cheating, rather than to ability or hard work. It is not clear whether this is based on the teacher's assumptions about the lack of potential of young people with chronic illnesses and/or of young black people. However, the net result is to communicate to the young person a low teacher expectation of her potential, a negative ethos that the young woman has to struggle against.

How young people relate to each other

School ethos also has to do with how the young people in the school are expected to behave towards one another. In our interviews, three young men and one young woman reported being physically abused in relation to their SCD. Others reported being teased and taunted about having 'yellow eyes', being skinny, being 'a slowcoach', being constantly unwell and away from school, or being a 'drama queen' for expressing their pain. One young person described the experience as follows:

'... oh, sickle cell, he is like, he is like one, one who cannot afford to run who cannot afford to do things, one who can die anytime ... people with sickle cell are better off dead when they are young, rather than living and suffering, you know, so you got to hear all that rubbish, so you know. ... [A friend] believes in like checking the genes and like and if they have sickle cell, it is like no, no, no, you should not have them. They should be terminated or something like that.'

(Interview 32, black African male, 25 years of age)

In this case the young person is upset by the pervasive negative discourse around SCD as a chronic illness, to the extent that even someone she regards as a friend is prepared to say to her that the birth of people with

SCD should be prevented, presumably by termination.

Bullying by young people and discriminatory discourses that go unchallenged suggest a negative school ethos. Another young person (Interview 33, British Asian male, 21 years of age) recounted a severe painful sickle cell episode that was triggered when he was assaulted by another young person at school. The head of the school year went to the home of the perpetrator and challenged the parents about their young person's bullying. In not tolerating a single instance of such antisocial behaviour, in engaging the parents as well as the young person, in using outreach rather than assuming that responsibility stops at the school gates, and in carrying through remedial actions consistently, the school arguably demonstrated a *positive ethos*.

How young people relate to staff

One possible indicator of school ethos is the relationship between young people and staff, and in particular the degree of inclusiveness within the school, and support or lack of it in relation to school re-entry after illness. The following field notes were taken during a visit to a local sickle cell support group to give feedback on the results of the questionnaire phase of the study.

'The mother was distraught because her 16-year-old son had been excluded from school a few weeks before his GCSE examinations. ... Her son has had a great deal of time off school with illness. He has not been achieving very well in his studies. Last week he got into a fight with other students around the issue of his frequent absences. The mother says this is the first time he has been in such trouble at school. However, the school have responded by excluding him for four weeks. The mother has asked the school why the length of exclusion has been so long for a first offence, and has twice asked the school to produce any evidence that this incident is in any way a culmination of poor behaviour at school. The school has not responded ... when challenged about the exclusion the school had backtracked and suggested that the exclusion was not formal but asked the boy to take 'study leave' covering two weeks before the Easter vacation and four weeks after. This was said to be to help him revise better for his GCSEs. ... the letter said that excluding the boy from school would take him away from the influence of a "negative peer group".'

(Field notes, 25 March 2009)

In this example the school apparently failed to challenge a group which it acknowledged to be a negative influence. Instead, having reportedly offered no support to the victim, it imposed a four-week exclusion for a first offence and compounded it by making the illegal suggestion that it should be construed as study leave, possibly to get a low-achieving young person off the books before exams that would influence league-table results.

How the school relates to the community

Carers of people with SCD described having to repeatedly go into school to educate teachers about SCD and their child's specific requirements. The notion of parent or carer as expert is one that some schools appeared to be reluctant to acknowledge. School ethos is in part about how the school positions itself in relation to the community. By implication, a school that refuses or is reluctant to acknowledge that parents or carers may be experts on their own children's health exhibits a poor school ethos. The majority of the parents reported a perception that, for their children, a school where there was a significant proportion or a majority of young black people helped with the acceptance of SCD as a legitimate issue, presumably because of the manner in which sickle cell has traditionally been constructed as a black issue rather than as a health issue (Dyson and Atkin, 2011). The following extract highlights how one parent was persuaded to talk to teachers about the condition of sickle cell, not only on behalf of her own child, but also on behalf of others with the condition:

'They persuaded me to give a talk to the school, and they bought some sickle cell videos for the library. So I worked with the school to empower them and also realised there were other children in the school which the school didn't recognise neither.'

(Case Study 1, black Caribbean mother)

Willingness to acknowledge a community of experts on whom schools can draw as a resource is fundamental to a school ethos which claims to recognise and value the relationship that the school has with the community. According to one respondent, preparedness to engage with the community can be readily demonstrated by a school through, for example, the simple act of inviting into the school members of voluntary organisations who can provide an opportunity to raise awareness among teachers, young people and parents of the implications of SCD in educational settings (Case Study 2, black Caribbean health professional).

Spiritual development

Integral to school ethos is the spiritual development of the child. Stuart (1999) argues that schools have to pay attention to the world in which young people live, all the elements of which contribute to spiritual development. People make choices as to whether or not spirituality is an important aspect of their daily life. Consequently, no individual, including teachers, can presume on behalf of another, including young people, the role that spirituality should or could play. Schools whose ethos includes the spiritual development of young

people should acknowledge their right to determine those aspects of self that they wish to share with or withhold from others. This is integral to the development of self-awareness, which is a key aspect of spirituality. A young person with SCD has the right to choose to disclose (or not) their disorder, and to whom (or not) they wish to disclose this aspect of themselves.

Classroom studies that are relevant and contribute to spiritual development may include sessions about personal and social issues. However, the extent to which classroom-based discussion is successful in assisting such development is dependent on the skills, attitudes, attributes and knowledge of the teachers. A school ethos that respects an individual's right to determine which aspects of the self to reveal to others may incur a tension between spiritual development and the need to keep others informed about an individual's SCD. The account provided by the following respondent mirrors this tension by highlighting the need for schools on the one hand to understand the disorder, while on the other respecting the right of parents and children to withhold information.

'It's very difficult, because I think you have to start from a process where, you know, people understand that this is a really serious condition, that can have serious effects, er, and you know end in a very serious way, and you will never get people to understand that unless people with it impact on society, put themselves out to say we've got the condition. Unfortunately some mothers or parents don't even make the school aware their children have SCD, because they still look at it as something to be ashamed of, and to be hidden, you know, they are worried about how people are going to, you know, deal with their child once they know their child has it.'

(Case Study 6, black Caribbean mother)

Moral development

A further aspect of school ethos is the attitude of the school towards the moral development of the young person. Moral development is more than the level of cognitive development, and more than teachers illustrating a set of values by their own behaviour and hoping that young people will emulate them (Kohlberg and Turiel, 1971). Moral behaviour has been said to necessitate a sense that young people can progress through stages of moral development. Each stage of this moral development represents a further de-centring of the egocentric viewpoint. Initially it starts with recognising that there are other interests. Subsequently this moral development entails accommodating one's views to the circumstances of, progressively, immediate others, wider society and a sense of good beyond immediate social norms. Moral education becomes less about promoting good behaviour through example,

and more about structuring learning to enable young people to progress, for example, through examination of moral dilemmas that challenge their world view. Others have distinguished between morality and convention, noting that intrinsic fairness and conventions that permit the smooth running of social groups are in different domains (Turiel, 1983), and that foregrounding concerns about justice and caring, respectively, may be gendered (Gilligan, 1982).

In the transcripts of the young people whom we interviewed, we identified evidence of moral considerations and reasoning. In the following example, the young person with SCD reflects on another student's reaction to his being granted time out from a school sports activity:

'There was this certain boy, and he, erm, he doesn't listen. He was just like, he knew I've got sickle cell, but he doesn't take it in. Erm, and sometimes I'm really, really tired and he was just like, erm, just like the teacher like when he was pushing and pushing to do that and (do you know like playing cricket) and I felt really tired and so I went to lie down, and he would like throw, like keep on throwing the ball at me like when I'm trying to rest.'

(Interview 31, black Caribbean male, 15 years of age)

When asked if the boy knew whether the young person had SCD, our respondent replied that he did, and when probed further about why the boy then behaved so badly towards him, our respondent replied:

'Because he, I think that, he just like thought it was a game, so, like, this wasn't the first time it happened, it had happened before this.'

In this extract the young person with SCD indicated that the other boy lacked a sense of decent behaviour towards him as someone with sickle cell. Ultimately he was not able to work out why the other boy behaved like this towards him, but added that 'I would just like something to happen so that people do take notice.' This suggests that different domains within the overall school ethos are intimately linked. The young person appeared to question his own sense of moral development because bullying (the domain of attitudes of young people to one another) was weakly addressed by the school.

In the following extract another young person with SCD reflected on the moral behaviour of a teacher:

'I had a really bad sickle cell in my legs, and I didn't want to leave the lesson, because I wanted to still stay, that's why. And I also asked the teacher if I could go and get water. And he's telling me, erm, no you can't, you can't have water in the lab. And I said, can I have it outside the class? I kept asking him and he just wouldn't listen so I just stayed and I sat there. And then another time with the same teacher that I has a really bad pain in my arm, and I thought like I'm going to go and get it [a drink of water], I'm going to get it and I went and got it. And he was like

‘Where did you go?’ And I said I needed to go and get water and you wouldn’t let me. And then he just left it, because he knew that he was being unfair.’

(Interview 26, black African female, 15 years of age)

This young woman indicated that she experienced sickle cell pain in class on more than one occasion, and asked permission to leave the classroom to have a drink of water in order to maintain her hydration. Permission was denied, but after the second request she left the classroom anyway. Upon her return she was challenged by the teacher, but when she provided a reasonable explanation for her absence, she suggested that a sense of fairness prevented the teacher from making negative comments or issuing any form of punishment.

In the following final example, a young man sets out the advice that he would give to teachers on dealing with a young person with sickle cell in their class:

‘I wouldn’t tell them to treat them differently or like telling them or treating them like children as if they’re disabled, but allowing them to go to the toilet and to get a drink and things like that. I think they should do that for the whole of the school. But I think I know why they don’t do that, because they’re trying to prevent truancy in the school. Probably that’s probably one of the reasons. But they need to consider both sides, I won’t say argument, because it’s not an argument, but both sides of the story from the different point of view, instead of just thinking for the school’s benefit and less for the pupils’ benefit, because the pupils’ benefit is the same as the school’s.’

(Interview 25, black African male, 15 years of age)

This young person would not like the school to treat young people with SCD any differently from others, for instance, as children, as less mature than their age, or as disabled. In his view anyone, not only those with SCD, should be allowed to go to the toilet during class. However, he could accept that this might cause the school authorities to worry about loss of control, make it easier for some people to truant and more difficult for the school to monitor everyone’s whereabouts. He concluded by arguing that the school ought to be organised around the needs of the students because young people were the essential component of the school.

In each of the three examples cited above the young person with SCD showed an acute appreciation of moral issues. They were at the receiving end of immoral behaviour from others and inconsiderate behaviour from teachers. They also showed a mature awareness of the possible tension facing the school staff between maintaining the conventions necessary to the smooth running of the school and what might constitute ethical behaviour towards the young person living with SCD.

However, what did not appear anywhere in our interview transcripts was a reference to any specific moral curriculum, framework or ethos that informed all social relationships within the school. This may be because, at the time of devising questions for the young people, we had not conceptualised school ethos as important, and so did not ask direct questions about this. It may be that none of the schools attended by our interviewees had a fully articulated moral education as part of their overall school ethos. This may partially explain the recurrence of negative experiences for young people with SCD even when the school had been told about their condition. In the absence of clear guidance on how moral education will be covered, any attempt to evaluate its efficacy is at best limited and at worst impossible. In contrast, a positivist approach to school ethos through formal expression of where, when and how moral development might be incorporated in the curriculum has the potential to be evaluated in terms of the young person’s experience of school.

Cultural development

In the UK there has been concern for some time about racism in schools (Tomlinson, 2008; Gillborn, 2008), and the potential of those with long-standing chronic illness to be disadvantaged in educational settings has been highlighted (Lightfoot *et al*, 2001). Young people with SCD may be at the centre of both of these scenarios. The black parents in our case studies were acutely aware of the possibility that their children might not achieve their full potential because of the negative expectations of their teachers regarding their academic potential and/or poor behaviour or attendance. The parents themselves might have experienced racism in British schools where, in the past, young black people were disproportionately represented in special schools:

‘We were embarrassed as children because what they showed us was negative. Africans with bones in their nose, women in the jungle, because that is the message that I was taught as a child in school.’

(Case Study 1)

Black parents may therefore be motivated to take an especially close interest in what happens to their children at school, quite apart from the usual parental concern. Even in primary school where, overall, smaller schools and more personal networks may make it easier to sustain a positive ethos, lack of cultural competency had a negative impact on the experience of the child and carer:

‘The first school he went to, a primary school, 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 we don't feel ... I think they felt quite threatened if I'm going to be blunt, about my husband, a 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? Which caused a lot of [friction] in the school and we had to withdraw [name] out of the school and found another school, erm, primary school where he started to settle down.'

(Case Study 1, black Caribbean mother)

In this example, the predominantly white school did not have the cultural competency to read the close interest taken by the father in the context of the history of discrimination in British schools, and instead it was reported to have reacted negatively to his attentiveness, choosing to view it as aggressive behaviour.

Social development

The most straightforward element of social development could be said to take place through extracurricular activities, especially those that take young people outside their immediate social environment and the presence of their parents or usual carers. School ethos can be judged by the extent to which all young people are included in such activities. One of the main vehicles for such social development is through the school trip, which was described by our respondents in both positive and negative terms. Some were included in all school trips:

'School trips, what about school trips, yeah, I went in school trips. I remember I went to France in a school trip, it was with my school and that was good. It was really nice.'

(Interview 40, black African male, 21 years of age)

On the other hand, a number of young people with SCD were excluded from certain school activities:

'Anything outside I was not, I was not allowed to take part in. I just have to stay back behind in the class. ... It makes me feel sad you know, everybody is doing something, and you are just looking out of the window seeing them enjoying themselves, laughing and running around. And then I am there, pretending to read a book. And I think to myself why I cannot be like them, why, why. And I think why me with sickle cell.'

(Interview 32, black African male, 25 years of age)

This type of exclusion can have other consequences, too, as the following extract suggests:

'Once I wanted to go to a school trip, you know. And they said, no, you cannot, and that the teacher would not allow me to go. The teacher at that time, she is like well, no, I cannot let you go because if something happened to you I don't know what to do with it, she would not like anything to happen to me. So, I was upset for not going and

participating in that trip. I really wanted to go, but what can I do, she said no.'

(Interview 35, black African male, 17 years of age)

According to these accounts, preventing young people with SCD from attending school trips or school sports days caused feelings of social isolation, and led to young people questioning the value of sharing information about their SCD if it resulted in further exclusion and discrimination. Even if specific activities were unsuitable for young people with SCD, some form of participation could be made possible, for instance through helping with timing, videotaping or reporting on events. Equality legislation requires schools to facilitate the inclusion of young disabled people, and could be used to develop a positive school ethos for those with SCD.

Conclusion

Young people with SCD report that they undergo negative experiences at school in relation to self-care. An examination of the relationship between reported exposure to negative experiences and the extent to which teachers and/or other young people reputedly know that a young person has SCD does not explain the patterns observed. This paper attempted to explain the diverse range of school experiences in other ways, particularly in relation to school ethos. We suggest that the relative experiences of young people with SCD at school depend on such factors as whether or not the school has coherent values that inform all aspects of school life (including the attitudes of young people and teachers to themselves and to each other), the nature of the links between school and community, and the extent to which spiritual, moral, cultural and social development forms an integral part of the school environment. Schools whose approach to behaviour management makes it impossible for young people to achieve their full potential contrast strongly with those in which young people, parents and teachers are deemed equal partners in achieving a positive school experience. Thus the school's approach to a range of whole-school policies is a determinant of school ethos, and may shed light on how an individual experiences school, irrespective of whether or not they disclose their SCD status. Schools that involve the community in activities relating to the welfare and education of children are shown to have a positive impact on parents, for if a child with SCD is to experience school positively, the school must also be experienced positively by parents.

Further research might assess the transferability of our ideas to other long-term conditions, examining the possible role of school ethos in supporting young

people with asthma, epilepsy and diabetes. Our work also demonstrates the importance of thinking about the school environment when talking about young people and their health or illness, and of broadening debates about diversity and health to include consideration of the interaction of the school environment and health.

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CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Sue E Dyson, Reader in Nurse Education, School of Nursing and Midwifery, Edith Murphy Building, De Montfort University, LE1 9BH, UK. Tel: +44 (0)116 201 3881; email: smccartney@dmu.ac.uk