Research paper

Education and young people with sickle cell disorder: a knowledge review

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What is known on this subject

- Knowledge reviews offer the potential for conceptual criticism rather than uncritical acceptance of published literature.
- Little has been written directly on sickle cell disorder and school education.
- Interventions in the social arrangements of schooling improve the education experiences of pupils with sickle cell disorder.

What this paper adds

- Most existing literature locates the problem within the person living with sickle cell disorders rather than within social arrangements.
- The social model of disability and chronic illness represents an important critique of existing literature.
- Improved policy and practice depends on studies that place sickle cell disorder and education into broader contexts including the socio-economic position of minority ethnic pupils; the historical moulding of the black family through racism; the way chronic illness is mediated by gender and ethnicity; and the competitive ethos of the UK school system.

ABSTRACT

Sickle cell disorders (SCD) are a group of chronic inherited blood conditions. The majority of studies on SCD have a clinical focus and deal with how those living with SCD 'manage' what is constructed as a given: the 'condition' of SCD. Consequently, many studies present the psychological impact, referring uncritically to what are termed 'coping strategies'. Current debates on SCD and other chronic conditions rarely engage with the broader social context. In part response to this, our paper presents a critical review of the literature on SCD, young people and education. The paper evaluates literature that touches on education and SCD, before concluding with a broad discussion of future research and policy priorities. Throughout, we reflect on how the process of constructing a knowledge base from available literature is problematic. We specifically discuss how current research presents a skewed picture of the experience of SCD, which is of limited value to those responsible for...
Introduction

Sickle cell disorders (SCD) are chronic inherited blood conditions affecting people from all ethnic groups, but particularly those of African, African-Caribbean, Mediterranean, Middle Eastern and Indian descent (Serjeant, 2001). Altogether, 21.4% of the primary school population in England record their ethnic origin in groups at higher risk of sickle cell (Department for Education and Skills, 2006). Thus, even without further inward migration or differential fertility, the future school population of England will comprise over one-fifth of pupils at higher risk of carrying genes associated with SCD, which is perhaps not surprising given that SCD is the most common genetic condition in the UK.

This paper presents a knowledge review on education and young people with SCD. There is comparatively little written directly on education. Rather, most SCD literature that either touches on education and/or has implications for education adopts a medical model, with education subordinated to the clinical consequences of the condition (see Anionwu and Atkin, 2001). We wish to transcend clinical approaches to chronic illness and focus more on the socio-cultural context of young people with SCD.

A knowledge review differs fundamentally from a systematic review. The latter is less suited to exploring the broader context in which evidence is produced, especially when faced with a contested area, such as ethnicity and SCD, where the focus of the actual research is often questioned, or is scarce, or is subordinated to other concerns (see Atkin and Chattoo, 2007). Moreover, we are concerned not only to present what the literature tells us, but also to interrogate it critically, so that the assumptions in the production of literature themselves become part of the analytical process (see Popay and Roen, 2003; Sellick and Howell, 2003).

Conducting the knowledge review

We adopted a systematic approach to collecting the material (see Samanta et al., 2005), although in analysing and writing up our findings, our approach was informed by knowledge review procedures developed by the Social Care Institute for Excellence (2007). Knowledge reviews provide a thematic exploration of the relevant literature, which can be useful in informing policy, especially when the evidence base for information is weak (Atkin et al., 2006).

The principal review questions were:

- What experiences in education do young people with SCD have?
- How do education services respond to the needs of pupils with SCD and their carers?
- What makes appropriate educational support for young people with SCD and their carers?
- To what extent do young people’s specific experiences of education relate to the broader experience of SCD?

The inclusion criteria for the review were that the material met at least one of the guiding review questions, was written in English, and was published between 1972 and 2007. The exclusion criteria included literature that focused only on sickle cell carriers or exclusively on clinical management, or was in the form of dissertations, abstracts, comments, letters, editorials or book reviews. A search of literature was conducted using databases and keywords as presented in Table 1.

This search produced numerous articles, including, for example, ones on the education of children with SCD about clinical aspects of their condition (Katz et al., 2002) or on increasing teacher knowledge of SCD (King et al., 2005), but few with a specific focus on school education and young people with SCD (see Table 2).
In order to aid the retrieval of key points from the references thus identified, a standard form was devised (see Appendix 1).

A total of 332 references judged potentially relevant were entered into the EndNote database programme, and in 238 cases the abstract and keywords were also incorporated into the database. A total of 94 full articles that met the main search criteria of education and young people with sickle cell disorder were reviewed.

### Presenting the themes identified in the literature

Most studies adopted psychological and clinical perspectives. The literature also positions young people with SCD within disabling discourses, referring to their ‘psychological adjustment’ (Hurtig and Park, 1989; Midence et al, 1993) and ‘coping strategies’ (Barbarin et al, 1999; Robinson, 1999; Royal et al, 2000; Thomas et al, 2001; Anie et al, 2002), with little recognition of the insights of the social model of disability (Oliver, 1990). This highlights how taking existing literature as ‘what we know’ presents a skewed picture of the experience of those with SCD, because it does not explore the social context in which the condition (or indeed the production of knowledge) occurs.

### An appraisal of existing accounts

Discrimination arising from SCD, as with any other chronic illness, has an impact on young people’s social life. However, the implications of this vary between individuals, different age groups, gender, and the socio-economic and cultural backgrounds of the young people (Darr et al, 2005). The literature, however, rarely reflects this and is dominated by psychological accounts, focusing on adjustment to the condition. Further, with the exception of Koontz et al (2004), studies involving intervention in the school environment to improve educational experiences were conspicuously lacking.

Isolation (Pinckney and Stuart, 2004), dependency, fear of illness, stigmatisation and hospitalisation, withdrawal from family and peers (Morgan and Jackson, 1986), poor self-image (Noll et al, 1992), depression (Barbarin et al, 1999; Rodrigue et al, 1996) and preoccupation with death (Boni et al, 2001) are reported as part of the experience of what it means to be a young
person with SCD. Consequently, commonly claimed psychological outcomes among young people with SCD include feelings of helplessness and worthlessness, stress, frustration, anxiety, self-blame, low self-image and esteem, depression and neurocognitive impairment. Furthermore, many studies, in keeping with their initial focus, maintain the importance of utilisation of psychological intervention, and recommend further research on patient education (Collins et al., 1998; Hasan et al., 2003; Helps et al., 2003; Barakat et al., 2006), cognitive-behavioural therapy (Anie, 2005), or special educational support to help improve the quality of life of patients (Morgan and Jackson, 1986; Adedoyin, 1992; Midence et al., 1993, 1996; Hilton et al., 1997; Thomas et al., 2001; Thomas and Taylor, 2002; Alao and Dewan, 2003; Anie and Green, 2006). Such interventions, however, seem to work for some people and not others, being sensitive to the context in which they are introduced (see Atkin et al., 2006).

What is apparent from the review is the absence of any clear-cut association between disease severity and outcomes (Barbarin et al., 1994; Burlew et al., 2000). Some individuals with SCD might develop psychological problems, but others do not (Burlew et al., 2000), consistent with the general literature on chronic illness (see Wist et al., 1986; Bury et al., 2005). Social factors account for more variability than the severity of the disease per se (Burlew et al., 2000). To be of value in understanding the experience of education this needs further investigation, and we return to this when we discuss the social context.

Some studies treat gender as a variable determining experience. For example, girls demonstrate more ‘adaptive’ behaviour than boys, who show somatic, immature, and cognitive deficits to a greater degree than their female counterparts (Brown et al., 1993). It is also argued that girls are better at withstanding the challenges of SCD (Anie and Green, 2006). However, Hill (1994) provides a sociological explanation for this. She proposes that mothers did not perceive SCD as a challenge or limitation for their daughters, who were ‘imagined’ as more able and more likely to care for themselves than boys. Further, the social expectations of both boys and girls are different, with boys expected to be aggressive, strong, masculine, and physically active, especially in sport. In the case of young people with

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SCD the effects of being black, poor and/or perceived as physically weak increase the significance of these norms and eliminate viable alternatives. The protective nature of mothers towards sons, for example, suggests culturally constructed gender norms that view black males as less capable of self-care, independent and more vulnerable to danger and risks. The gender care-giving strategies of some mothers, and the adverse impact of SCD on the lives of boys, reflect the narrow range of acceptable gender role options available to low-income black male children (Hill and Zimmerman, 1995).

This reflects broader findings that socialisation and gender expectations differ between boys and girls, and may affect their development and how they perceive their illness (see Williams, 2000). We now consider the wider implications of this when interpreting the literature. As we have seen, much of the work in this area does not locate the experiences of young people with SCD within a broader social context, including the contexts of disability discrimination, racism, and socioeconomic status, and will tend to list such negative characteristics as inevitable by-products of living with SCD, rather than as constituted through social structures that are particular to time and place.

There are many studies that claim SCD has a significant impact on social functioning including emotional (Noll et al, 1996), recreational and educational (Robinson, 1999; Thomas et al, 2001; Peterson et al, 2005), and vocational activities (Palermo et al, 2004). The problem with such studies, however, is that they assert either a form of biological reductionism (the life of someone with SCD reduced to their ‘condition’), or a type of psychological reductionism, in which the role of discriminatory structures, racism, poverty, and the lack of legislative and policy frameworks in supporting the lives of young people with SCD are ignored. Many of these studies lack comparators with either other young people, those living with chronic illness, or others experiencing racism. Young people with SCD face the same challenges faced by all young people, and although having a chronic illness can make the negotiation of being a young person more difficult, it does not necessarily dominate a person’s identity (Atkin and Ahmad, 2001).

Towards a sociological account

There appears to be little recognition in many accounts of the extent to which the alleged psychological concomitants of SCD disappear when social interventions are made. Thus, teacher and peer education on sickle cell, challenges to negative labelling, establishing measures to help prevent crises, knowledge of early signs and symptoms, and reassurance of parents by consistent action that teachers and peers are knowledgeable and supportive are, collectively, reported to have improved school experiences for people living with SCD (Koontz et al, 2004).

The quality of life for young people with SCD can be more affected by the way people around them respond to them than by their condition. Nonetheless, without the wider consideration of disabling structures and enabling social environments, any approach seeking to positively influence the lives of adolescents with SCD ends up promoting social adjustment (Pinckney and Stuart, 2004) with SCD reified as the cause of problems. This leaves the prevailing social structures of racism, of disability discrimination (see Dooley and Perkins, 1998), and of unequal life chances in education, housing and employment, as well as the context of being a young person out of account. It also leaves open the door for those young people with SCD who do not adjust to be blamed for their circumstances.

The medical and psychological dominance of much SCD literature means that the term ‘social’ itself tends to be reduced to a narrow concept of interpersonal relationships (see Rodrigue et al, 1996). Conclusions that SCD can be disruptive to family life are dis-embedded from context. The black family has itself been moulded by a long history of racism, and of discrimination in employment and criminal justice (Hill, 1994). This results in high levels of lone motherhood and high levels of female participation in paid labour. Conversely, wider employment discrimination means low levels of participation in formal labour markets for black males, with consequences for gender relations in such communities. Overlying family forms structured by racism, there are also longstanding issues of discriminatory attitudes in health services, and confusion between SCD and sickle cell carriers (see Anionwu and Atkin, 2001).

In contrast to some psychological studies, Hill (1994) and Anionwu and Atkin (2001) argue that social factors shape the course and severity of the illness. Such factors include proper access to healthcare facilities, positive attitudes of healthcare providers, gender roles, and the employment status of the individuals. This is perhaps not surprising, as the broader sociological literature reminds us that social standing in a series of hierarchies, as well as social support, is itself a key determinant of health (Wilkinson, 1996).

The meanings of SCD and its relevance to education

What are the specific implications of these rather general debates for education? In the first instance, there are several ways in which the clinical and psychological focus of the literature finds expression in
education strategies. The physical features of people with SCD are said to include small body structure, sensitivity to environmental changes such as heat and cold, body weakness and yellow eyes (Robinson, 1999; Wilson et al, 2003). Such concerns can dominate debates about education and schooling. When policy and practice guidance does exist, it tends to advise teachers about the possible physical impact of the condition on the child’s schooling (see Atkin and Ahmad, 2000). Teachers, for example, are advised to make sure a child is not exposed to the cold after going swimming, takes a rest when tired, is excused physical exertion, or is allowed to visit the toilet more regularly than other children, because of their need to drink plenty of fluids (see Dooley and Perkins, 1998). Such advice, although potentially helpful, can present a one-dimensional concern with SCD, which emphasises possible physical limitation and thereby fails to recognise how people may be embodied in different ways, within different systems of meanings, and positioned with varying degrees of social leverage (Turner, 1996). In effect, the physical body of the young person with SCD is essentialised in a parallel manner to the reification of their psychological experiences discussed above.

In this way, the manner in which young people with SCD ‘physically adjust’ to their illness and cope with it is held to be important, especially within the context of their engagement with education (Morgan and Jackson, 1986; Lee et al, 1997). However, the ways in which young people with SCD perceive their physical appearance do not depend primarily upon the severity of illness, or merely on the age and gender of the individuals. They also depend upon the strength of their social support, their socio-economic and cultural background, social constructions of the allegedly normal and imagined body, and constructions of variation from the normality as impairment (Shakespeare, 1995). By contrast, many young people and their siblings learn to live positively with SCD and normalise their lives (Royal et al, 1995; Atkin et al, 1998b). Conceptualising the experience of children within a more social model of disability frames people as active agents who engage with their SCD, and not as passive tragic victims of the condition (Swain et al, 2004). We return to this in our discussion. For all the positive contributions of the social model of disability in helping to contextualise research on SCD, this approach has limitations when considering pain, for not all pain can be dissolved through enabling school environments (Hughes and Paterson, 1997). Severe pain is one of the features of SCD, and negotiating a life with both chronic and intermittent acute pain is a challenge facing many young people with SCD, including during their time at school (Maikler et al, 2001; Palermo et al, 2004; Jacob et al, 2006). Responding to the disruption of other activities such as sleep, eating and socialising may also require addressing within school policies on SCD, although to be consistent with our previous arguments, such policies need to recognise the social consequences of pain, which requires management in a non-clinical environment, rather than reduce it to a clinical event.

More broadly, regular school participation is seen as essential to children’s education and social development as well as their psychosocial wellbeing (Fowler et al, 1986; Nash, 1989; Midence and Elander, 1994; Fuggle et al, 1996), but there is little substantial research that explores these issues in detail. Interruption to schooling and peer relationships is a particular difficulty facing children with a chronic illness (Mador and Smith, 1989; Davis and Wasserman, 1992; Shapiro et al, 1995; Wjst et al, 1996; Darr et al, 2005), and indeed the onset of painful crises or other clinical complications can disrupt education for those with SCD (Noll et al, 1996; Schatz et al, 2001; Koontz et al, 2004). Children with SCD may have restrictions placed on their physical activities and commonly experience fatigue that can make it difficult physically to keep up with peers (Noll et al, 1996). School activities can be further limited by hospitalisation, clinic visits or restrictions imposed by the expectations of others (Nettles, 1994).

In interrogating the literature in detail, similar problems regarding focus emerge. Much literature is concerned with the poor academic performance and achievement of pupils with SCD, rather than collective educational systems of support or policies (Atkin and Ahmad, 1998; Thomas and Taylor, 2002). Further, the literature on academic performance has been inconsistent and controversial. Some studies suggest that poor education outcome is a consequence of how the illness affects cognitive processes. Such studies tend to skew our understanding of the condition, particularly when findings are discussed in relation to IQ—a hotly debated topic, when raised in relation to ethnic minority populations (Demaine, 1989). Other authors (Hurtig and Park, 1989; Midence et al, 1996; Richard and Burlew, 1997), however, have found no evidence to support a relationship between illness severity and academic achievements. These findings tend to emerge from better designed studies, which include comparator groups, as well as having sufficient power (see Atkin et al, 2006). A feature of the literature, more generally, is that studies on educational attainment vary in the type of comparison groups used, such as clinic users, children with chronic illnesses, peer groups and siblings. Studies also offer little in the way of comparison groups or control for variables such as age, gender, ethnicity and economic status (Barbarin et al, 1999). It is, therefore, difficult to draw any firm conclusions from such evidence.

Nonetheless, the literature raises the possibility that affected children could lose out academically and become isolated from friends and peers (Conyard et al,
1980; Armstrong et al, 1996; Maikler et al, 2001; Schatz, 2004), although response to the clinical consequences of the condition, as we have seen, varied between individuals and, according to different authors, depends on individuals’ gender, age, stage of illness and social and cultural background (Gil et al, 1996; Murray and May, 1998; Barry and Elander, 2002; Anie and Steptoe, 2003; Dunlop and Bennett, 2006; Swain et al, 2006). Further, we need to avoid generalisations or the use of stereotypes in predicting how a particular person from a particular culture will express feelings of pain (Helman, 2007). Indeed, the realm of the cultural background of individuals with SCD is fraught with the danger of stereotyping, including stereotypes of allegedly different pain thresholds and of drug-seeking behaviour (Anionwu and Atkin, 2001). There is some evidence that teachers might not take a person’s symptoms seriously, as they think they are attention seeking or being disruptive (Atkin and Ahmad, 2000).

The school context, therefore, can be important in how a person makes sense of their illness. During schooling hours, young people with SCD interact with their peer groups and teachers, and are influenced by how other people interact with them (Koontz et al, 2004). Young people’s positive attitude and attitudes of teachers and peers in handling pain, for instance, makes the SCD condition easier (Gil et al, 2000). More broadly, this would suggest a shift in the current focus of literature, away from the individual to the organisational context, which interprets and responds to a person’s condition. There is little literature that attempts this, and even this work is not research based (Dyson, 1992).

Nonetheless, themes do emerge, and these could help inform future research as well as policy and practice. Evidence suggests, for example, that a lack of understanding on the part of schools creates many difficulties for young people and, as a result, they often do not fulfil their potential (Chua-Lim et al, 1993; Barbarin et al, 1994; Shapiro et al, 1995; Fuggle et al, 1996; Atkin and Ahmad, 2000, 2001; Darr et al, 2005). Not uncommonly, teachers are unable to deal with potential crises at school (Midence and Elander, 1994; Broome et al, 2001). Parents comment on the ignorance of many teachers, who feel that children exaggerate the consequences of the illness (Atkin et al, 1998a). More generally, families and individuals describe education services as unresponsive to their needs (Midence and Elander, 1994). Most young people feel their illness has affected their academic progress (Atkin and Ahmad, 2001), although they actively attempt to overcome the disruption it has caused (Fuggle et al, 1996). Neither do schools seem to offer much support in overcoming these disruptions (Midence et al, 1992; Shapiro et al, 1995; Atkin and Ahmad, 2000, 2001; Darr et al, 2005). Few schools, for example, seem to have policies on how to respond when a child misses school with SCD (Darr et al, 2005), and are rarely able to offer flexible tutoring or individualised educational plans (Dooley and Perkins, 1998). Anionwu (1992) suggests greater liaison between the school, home and hospital particularly when the child is off sick. Holman (1997) concurs and presents a protocol that has been developed for the school nurse to help the child in the school environment. School support programmes can also help improve communication among family, school and healthcare providers, and some studies suggest that meetings between different parties are beneficial. Individually tailored SCD school intervention programmes could address relevant issues such as absenteeism, academic difficulties, general disease management and pain (Gil et al, 2000).

Few young people had received helpful careers advice at school (Atkin and Ahmad, 2001), despite it being especially important for those with a chronic illness (Nettles, 1994), although the indifference of careers officers was sometimes attributed to racism (Braham et al, 1992; Atkin and Ahmad, 2001). This, in turn, raises the issue of employment and employment training. People with SCD may find themselves excluded from labour markets because of a lack of support, or as a consequence of employers’ ignorance, inflexibility and inability to accommodate difference (Franklin and Atkin, 1986; Barrett et al, 1988; Evans, 1998; Anionwu and Atkin, 2001; Darr et al, 2005). The potential for education to become a resource to fight such discrimination could be the subject of research to understand the relationship between chronic illness, ethnicity and exclusion from labour markets (see Ali et al, 2006). Without such research, it is difficult to formulate successful education policies.

Discussion

There is a dearth of literature exploring the educational experience of those with SCD. The literature that does exist often discusses education in passing, subordinated to a more clinical or psychological focus, and is concerned with individual adaptation. Such research tends to essentialise a person’s experience of the illness, in which they are seen to ‘manage’ what is constructed as a given – the condition. Problems, therefore, tend to become located within the individuals rather than the context they live within.

Relying solely on such an approach may present a skewed account of SCD and education, meaning that emerging insights need to be heavily contextualised, in a way that recognises that illness behaviour is part of a socially defined status. To this extent, interpretation of the evidence becomes as important as the evidence itself (see MacDonald, 2003) and this offers a reminder of how doing research is not a neutral or objective
process, but embodies contested ideas, created and given meaning through the exercise of social power at specific sites of praxis (Alvesson and Sko¨ldberg, 2000).

The limitations of the current literature suggest the importance of broadening the narrow focus of current debates. This requires greater engagement with the social context within which people live their lives. Chronic conditions, such as SCD, have consequences that transcend the initial illness narrative (Nettleton, 2005). Illness is simply one aspect of a person’s identity (Bury et al, 2005), and studies often fail to contextualise the experience of people with a chronic illness with the experience of ‘being’ more generally. For example, many young people with SCD and their siblings learn to live positively with chronic illness and normalise their lives (Atkin et al, 1998b; Royal et al, 1995).

This begins to introduce the value of conceptualising the experience of children within a more social model of disability, which emphasises the value of conceptualising people as active agents who engage with the condition, and not as passive tragic victims of conditions such as SCD (Swain et al, 2004). Disability thus becomes a social issue, in which systematic discrimination not only leads to relative dependence and loss of choice for disabled pupils, but also excludes them from activities and roles taken for granted by the majority of the school population (Corker and French, 1998).

The social model of disability, however, does have drawbacks. First, authors on disability rights and on ethnicity do not always share common ground (see Ahmad, 2000), and in this respect ‘independence’ may be a particular cultural construct, embodying western assumptions (Atkin and Chattoo, 2007). In education research this could direct our attention to investigate, for example, the extent to which young people with SCD value being able to depend upon peers to speak up for them rather than always themselves having to repeatedly account for their SCD. Second, the social model of disability cannot always explain the lived experiences of pain, even though social tragic victims of pain from health and social care agencies do exacerbate the consequences of the illness and make the experience of pain far worse for those with SCD and their families (see Amionwu and Atkin, 2001). Research in school settings could thus be directed to finding what contexts make teachers more or less likely to believe a young child with SCD when they say they are in pain.

Pupils with SCD are subject to marginalisation, in terms of both disability structures and racism. While the health-related complications of SCD are undoubtedly challenging, enabling social environments, for example, pride in ethnic identity (Bediako, 2007), can be constructed that significantly change the illness experience. This is all the more important as young people spend a significant amount of their time in education settings. It is a lack of educational policies and proactive intervention on the part of teachers, rather than sickle cell per se, that may lead to academic failure, limited career options and negative self-images. School interventions to improve student experience in schools have received limited coverage. Furthermore, there is lack of knowledge and appropriate resource allocations to integrate young people with SCD in mainstream educational institutions, and questions as to whether health professionals can bridge the gap between healthcare providers, students, teachers and parents (Day and Chismark, 2006).

To establish the nature and extent of disabling structures, discriminatory attitudes and racist discrimination facing young people with SCD in their education, a research programme on SCD and education is required. Evidence derived from the experiences of young people with SCD and their carers is a necessary, though not a sufficient, prerequisite to creating enabling school environments. In this respect, there is a further feature of the literature that hinders development of an evidence base in education and SCD. Debates about SCD tend to take place in isolation from more mainstream debates about chronic illness. SCD has much in common with other chronic conditions (see Atkin and Ahmad, 2000). Consequently, the mainstream literature on chronic illnesses can help make further sense of the educational experience of those with SCD as they regularly have to reconstitute the relationship between their body, self and illness (Bury et al, 2005). Insights from the broader literature on chronic illness might help compensate for the lack of specific literature on SCD and education. SCD shares similarities with conditions such as cystic fibrosis, diabetes, asthma and rheumatoid arthritis. Successful education provision for these conditions has the potential to have similar success for those with SCD.

Finally, our account is a reminder that evidence exists in a context in which it assumes a social, economic, moral and political meaning (see Bauman, 1992). Furthermore, offering an analysis of the education problems facing people with SCD is one thing: doing something about it is another. Often there is a gap between our understanding and our willingness to act to improve practice. A commitment to change, informed by critical insight, is essential in ensuring research informs policy (see Taylor, 1994). In practical terms, focused evaluative studies exploring specific interventions would be a welcome addition to an emerging research agenda. Exploring what innovative practice occurs in this area would be equally valuable. At the same time, another tension emerges: relying on evidence to drive interventions creates the danger of doing nothing. We would not wish to stifle innovation by calling for research before such innovation is enabled, particularly since we are aware of the practice
of using research as an excuse for inaction, especially in debates about meeting the education and care needs of minority ethnic populations (see Atkin, 2004). There are, however, relatively few well-designed studies on which we can base future interventions. In the absence of robust evidence, this perhaps further emphasises the importance of reconciling our existing evidence in broader practice and theoretical debates, in order to maximise the value of what we do know.

For example, by embedding debates about education and SCD within more general discussion about ethnicity, diversity and differences, we are able to understand the extent to which ideas such as institutional racism explain inaccessible and inappropriate provision, as well as the importance of understanding how a person’s cultural and ethnic background enables them to make sense of having a chronic illness. A useful example from the USA is how the original chronic care model was expanded to include additional change concepts, one of which was cultural competence (see Congress on Improving Chronic Care, 2002, p.3). At the same time, however, we need to accept that in some ways minority ethnic populations might not be that different from the general majority population. Overall improvements in education policy and practice could have benefits for everyone. Equally, engaging with organisational and professional culture helps explain the dynamic tensions in enacting policy and practice (Atkin and Chattoo, 2007). Understanding this can be as important as understanding a person’s experience of SCD. This finds resonance in current debates about culturally competent practice in health and social care, which emphasise the importance of getting practitioners to challenge their own values, develop understanding and sensitivity, and apply their awareness and knowledge to appropriate practice (Papadopoulos et al, 2004), while recognising the organisational context in which they work (Dominelli, 2004). The starting point for successful policy and practice guidance, therefore, becomes an analysis of the present difficulties, an explanation of how these difficulties are currently made sense of, and a presentation of alternative ways of making sense of the situation. This review, by providing a critical overview of current evidence, offers a starting point from which to develop more informed practice and policy in SCD and education.

**Conclusion**

A search for literature on sickle cell and school education produces few directly relevant references. Clinical literature seems content to read off educational consequences from the condition itself, while psychological literature frames ongoing problems as ones requiring the person with SCD to adjust. In contrast, a sociological approach tends to emphasise continuities with other chronic illnesses, with the experiences of other minority ethnic pupils, and indeed with all other peers. Further, such approaches see attitudes and behaviours as a function not of SCD itself, nor of maladjustment, but as socially and historically derived, and thereby amenable to effecting changes through challenges to current social arrangements.

The gateway to education issues that is proffered by a clinical and psychological focus is one-dimensional. The focus is on educational non-attendance and relative failure, on physical and performative differences that mark out such children from their peers, and on physical symptoms that frame the young person as passive and eternally vulnerable.

A knowledge review, of the type we have conducted here, offers other avenues to explore in researching education and young people with SCD: ones that are mindful of the context for all young pupils with chronic illnesses; of the socio-economic position of minority ethnic pupils in UK schools; of the manner in which family has been historically moulded by racism; of the gendered as well as ethnic mediators of chronic illnesses; and of the normalising, testing and performative ethos of current school practices. In turn, these avenues offer more plausible ways of working towards an inclusive education for young people with SCD and other chronic illnesses. This review outlines some conditions for more successful interventions, in which the emerging evidence can engage with and develop existing examples of innovative practice.

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**REFERENCES**


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CONFLICTS OF INTEREST

None.

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### Appendix 1: Knowledge review form

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*Code for rating: A, very relevant to the research questions; B, relevant; C, partially relevant; D, of little relevance; E: not at all relevant*