Research paper

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

Hala Abuateya BA MA PhD
Senior Research Fellow, Unit for the Social Study of Thalassaemia and Sickle Cell, De Montfort University, Leicester, UK

Karl Atkin BA DPhil
Senior Lecturer, Department of Health Sciences, University of York, UK

Lorraine A Culley BA MA PhD
Professor of Social Sciences in Health, Mary Seacole Research Centre

Sue E Dyson RN RM BSc MSc EdD
Head of Nursing and Midwifery Research

Simon M Dyson BSc(Soc) MPhil PhD
Director, Unit for the Social Study of Thalassaemia and Sickle Cell

De Montfort University, Leicester, UK

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

education policy and practice. The paper concludes that research should move beyond describing the basic health needs of people with SCD by including the social context of their lives. Existing literature on the individual educational experiences of young people living with SCD is, however, either dated or limited by being based on conceptual argument rather than empirical data. Consequently, there is a need for well-designed studies to establish the best way to meet the educational needs of young people with SCD, reflecting not only their health needs in school, but the whole context of living with SCD, including interaction with disabling or racist structures. Furthermore, this holistic approach could contribute to a wider understanding of the educational needs of young people from minority ethnic backgrounds and of young people living with chronic illnesses.

Keywords: chronic illness, education, England, sickle cell, social context, young people

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).

Table 1 Databases searched and search strategy

Criteria	Specification (1972 onwards unless stated)
Databases	Academic Search Elite (EBSCO)
	Applied Social Sciences Index and Abstracts (ASSIA)
	CINAHL – Cumulative Index to Nursing and Allied Health Literature
	British Education Index – 1975 to date
	ERIC – 1966 to date
	International Bibliography of Social Sciences (IBSS) – 1951–2007
	Medline (PubMed)
	PsycINFO
	Science Direct
	Social Sciences Citation Index
	Scopus
Search type	Keywords, abstract, subject heading and free text
Keywords in each database	*People*: young people, adolescents with sickle cell, children, young adults, adoles*, youth and pupil*
	Disease: sickle cell*, haemoglobinopathy; haemoglobin disorder, disabilities, chronic illness, silent stroke, anem*
	Education: schools, education, learning, academic achievement, educational attainment, school, college, curriculum
	Other topics: ethnic minority, racism, discrimination, deprivation, coping strategies, pain crisis, psychological impact
Language	English
Publication type	Research articles and peer-reviewed materials

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

Table 2 Search outcomes for databases: number of articles found

List of databases	Sickle cell*	Sickle cell* and adoles*	Sickle cell* and child*	Sickle cell* and educ*	Sickle cell* and scho*	Sickle cell* and learn*
Academic Search Elite (EBSCO)	1625	473	34	7	10	2
Applied Social Sciences Index and Abstracts (ASSIA)	172	78	94	26	29	29
CINAHL – Cumulative Index to Nursing and Allied Health Literature	1217	319	312	80	31	6
British Education Index – 1975 to date	11	1928	11	37	15	6
ERIC – 1966 to date	3850	14	7	37	8035	6
International Bibliography of Social Sciences (IBSS)						
1951–2007	68	6	8	2	–	–
Medline (PubMed)	16 101	4332	2376	78	253	19
PsycINFO	613	158	119	173	168	161
Science Direct	2391	52	496	34	15	5
Social Sciences Citation Index	4378	136	1001	68	47	12
Scopus	13 984	3572	4793	491	613	72

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 Wjst *et al*, 1996; 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

SCD the effects of being black, poor and/or perceived as physically weak increase the significance of these norms and eliminate viable alternatives. The protectiveness 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 disembedded 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 Sköldberg, 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 responses to 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 Anionwu 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 important 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.

REFERENCES

Adedoyin MA (1992) Psychosocial effects of sickle cell disease among adolescents. *East African Medical Journal* 69:370–2.

Ahmad WIU (2000) Introduction. In: Ahmad WIU (ed) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press, pp. 1–11.

Alao AO and Dewan MJ (2003) Psychopathology in sickle cell disease. *West African Journal of Medicine* 22:334–7.

Ali N, Atkin K, Craig G *et al* (2006) *Ethnicity, Disability and Work: examining the inclusion of people with sensory impairments from black and minority ethnic groups into the labour market.* London: RNIB.

Alvesson M and Sköldber K (2000) *Reflexive Methodology: new vistas for qualitative research.* London: Sage.

Anie K (2005) Psychological complications in sickle cell disease. *British Journal of Haematology* 129:723–9.

Anie K and Green J (2006) Psychological therapies for sickle cell disease and pain. *The Cochrane Library* 4:CD001916.

Anie K and Steptoe A (2003) Pain, mood and opioid medication use in sickle cell disease. *Hematology Journal* 4:71–3.

Anie K, Steptoe A, Ball S *et al* (2002) Coping and health service utilisation in a UK study of paediatric sickle cell pain. *Archives of Disease in Childhood* 86:325–9.

Anionwu EN (1992) Sickle cell disorders and the school child. *Health Visitor* 65:120–2.

Anionwu EN and Atkin K (2001) *The Politics of Sickle Cell and Thalassaemia*. Buckingham: Open University Press.

Armstrong FD, Thompson RJ, Zimmerman R *et al* (1996) Cognitive functioning and brain magnetic resonance imaging in children with sickle cell disease. *Pediatrics* 97:864–70.

Atkin K (2004) Primary health care and South Asian populations: institutional racism, policy and practice. In: Ali S and Atkin K (eds) *South Asian Populations and Primary Health Care: meeting the challenges*. Oxford: Radcliffe Publishing.

Atkin K and Ahmad WIU (1998) Genetic screening and haemoglobinopathies: ethics, politics and practice. *Social Science and Medicine* 46:445–8.

Atkin K and Ahmad WIU (2000) Living with sickle cell disorder: how young people negotiate their care and treatment. In: Ahmad WIU (ed) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press, pp. 45–66.

Atkin K and Ahmad WIU (2001) Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science and Medicine* 53:615–26.

Atkin K and Chattoo S (2007) The dilemmas of providing welfare in an ethnically diverse state: seeking reconciliation in the role of a 'reflexive practitioner'. *Policy and Politics* 35:379–95.

Atkin K, Ahmad WIU and Anionwu EN (1998a) Screening and counselling for sickle cell disorder and thalassaemia: the experience of parents and health professionals. *Social Science and Medicine* 47:1639–51.

Atkin K, Ahmad WIU and Anionwu EN (1998b) Service support to families caring for a child with a sickle cell disorder or thalassaemia: the experience of health professionals, service managers and health commissioners. *Health* 2:307–27.

Atkin K, Rodney A, Cheater F *et al* (2006) *Providing Support for People with SCD and Thalassaemia Disorders and their Families: a review of the evidence and guidance for good practice (Project Ref. 0300078)*. Systematic review submitted to the Department of Health Policy Research Programme. York: University of York.

Barakat LP, Lash LA and Lutz MJ (2006) Psychosocial adaptation of children and adolescents with sickle cell disease. In: Brown RT (ed) *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: a biopsychosocial approach*. New York: Oxford University Press, pp. 471–95.

Barbarin OA (1994) Risk and resilience in adjustment to sickle cell disease: integrating focus groups, case reviews and quantitative methods. In: Nash KB (ed) *Psychosocial Aspects of Sickle Cell Disease: past, present and future directions of research*. New York: The Haworth Press, pp. 97–121.

Barbarin OA, Whitten CF and Bonds SM (1994) Estimating rates of psychosocial problems in urban and poor children with sickle cell anaemia. *Health and Social Work* 19:112–19.

Barbarin OA, Whitten CF, Bond S *et al* (1999) The social and cultural context of coping with sickle cell disease: III. Stress, coping tasks, family functioning, and children's adjustment. *Journal of Black Psychology* 25:356–77.

Barrett DH, Wisotzek IE, Abel GG *et al* (1988) Assessment of psychosocial functioning of patients with sickle cell disease. *Southern Medical Journal* 81:745–50.

Barry T and Elander J (2002) Pain coping strategies among patients with haemophilia. *Psychology, Health and Medicine* 7:271–81.

Bauman Z (1992) *Intimations of Post Modernity*. London: Routledge.

Bediako S (2007) Racial centrality and health care use among African American adults with sickle cell disease. *Journal of Black Psychology* 33:422–38.

Boni L, Brown R, Davies P *et al* (2001) Social information processing and magnetic resonance imaging in children with sickle cell disease. *Journal of Pediatric Psychology* 26:309–19.

Braham P, Rattansi A and Skellington R (1992) *Racism and Anti-Racism: inequalities, opportunities and policies*. London: Open University Press and Sage.

Broome ME, Maikler V, Kelber S *et al* (2001) An intervention to increase coping and reduce health care utilisation for school-age children and adolescents with sickle cell disease. *Journal of National Black Nurses Association* 12:6–14.

Brown R, Armstrong D and Eckman J (1993) Neurocognitive aspects of pediatric sickle cell disease. *Journal of Learning Disabilities* 26:33–45.

Burlew K, Telfair J, Colangelo L *et al* (2000) Factors that influence adolescent adaptation to sickle cell disease. *Journal of Paediatric Psychology* 25:287–99.

Bury M, Newbould J and Taylor D (2005) *A Rapid Review of the Current State of Knowledge Regarding Lay Led Self-Management of Chronic Illness*. London: National Institute for Health and Clinical Excellence.

Chua-Lim C, Moore RB, McCleary G *et al* (1993) Deficiencies in school readiness skills of children with sickle cell anaemia: a preliminary report. *Southern Medical Journal* 86:397–402.

Collins M, Kaslow N, Doepke K *et al* (1998) Psychosocial interventions for children and adolescents with sickle cell disease (SCD). *Journal of Black Psychology* 24:432–54.

Congress on Improving Chronic Care (2002) *Innovations in Research and Practice*. www.improvingchroniccare.org/downloads/2002_summary_copy3.pdf (accessed 1 March 2008).

Conyard S, Krishnamurthy M and Dosik H (1980) Psychosocial aspects of sickle-cell anaemia in adolescents. *Health and Social Work* 5:20–6.

Corker EM and French S (1998) *Disability Discourse*. Buckingham: Open University Press.

Darr A, Atkin K, Taylor S *et al* (2005) *Chronic Illness, Ethnicity and Young People: how those with a sickle cell or thalassaemia disorder negotiate the life transitions associated with growing up: evaluating development activity*. Evaluation report (Project No: URNRG24031). Birmingham:

Midlands Sickle Cell and Thalassaemia Society (formerly OSCAR Birmingham).

Davis JK and Wasserman E (1992) Behavioural aspects of asthma in children. *Clinical Paediatrics* November:678–81.

Day D and Chismark E (2006) The cognitive and academic impact of sickle cell disease. *Journal of School Nursing* 22:330–5.

Demaine J (1989) Race, categorization and educational achievement. *British Journal of Sociology of Education* 10:195–214.

Department for Education and Skills (2006) *Maintained Primary Schools Number and Percentage of Children by Ethnic Group Table 32; Maintained Secondary Schools Number and Percentage of Children by Ethnic Group Table 33.* www.dfes.gov.uk/rsgateway/DB/SFR/s000682/SFR38 –2006web3.xls (accessed 1 March 2008).

Dominelli L (2004) *Social Work: theory and practice for a changing profession.* Cambridge: Polity Press.

Dooley EA and Perkins N (1998) Let's talk about needs of African American children with sickle cell disease: a recognized 'other health impairment'. In: *Coming Together: Preparing for Rural Special Education in the 21st Century.* Proceedings of the 18th American Council on Rural Special Education, 25–28 March, Charleston, SC.

Dunlop R and Bennett K (2006) Pain management for sickle cell disease (Cochrane Review). *The Cochrane Library, Issue 4.* Oxford: Update Software.

Dyson SM (1992) Blood relations: educational implications of sickle cell anaemia and thalassaemia. In: Booth T, Swann W, Masterton M *et al* (eds) *Curricula for Diversity in Education (Learning for All 1).* London: Routledge, pp. 277–83.

Evans C (1998) Children with sickle cell anaemia: parental relations, parent–child relations and child behaviour. *Social Work* 33:127–30.

Fowler MG, White JK and Redding-Lallinger R (1986) Neuropsychological deficits among school age children with sickle cell disease. *American Journal of Diseases of Childhood* 140:297–313.

Franklin I and Atkin K (1986) Employment of persons with sickle-cell disease and sickle cell trait. *Journal of the Society of Occupational Medicine* 36:76–9.

Fuggle P, Shand P, Gill LJ *et al* (1996) Pain, quality of life and coping in sickle cell disease. *Archives of Disease in Childhood* 75:199–203.

Gil KM, Wilson JJ, Orringer E *et al* (1996) Effects of cognitive coping skills training on coping strategies and experimental pain sensitivity in African American adults with sickle cell disease. *Health Psychology* 15:3–10.

Gil KM, Porter L, Ready J *et al* (2000) Pain in children and adolescents with sickle cell disease: an analysis of daily pain diaries. *Children's Health Care* 29:225–41.

Hasan SP, Hashmi S and Alhassen M (2003) Depression in sickle cell disease. *Journal of the National Medical Association* 95:533–7.

Helman CG (2007) *Culture, Health and Illness* (5e). New York: Oxford University Press.

Helps S, Peterson C, Udwin O *et al* (2003) Psychosocial and neurocognitive aspects of sickle cell disease. *Child and Adolescent Mental Health* 8:11–17.

Hill SA (1994) *Managing Sickle Cell Disease in Low Income Families.* Philadelphia: Temple University Press.

Hill SA and Zimmerman MK (1995) Valiant girls and vulnerable boys: the impact of gender and race on mothers' care-giving for chronically ill children. *Journal of Marriage and Family* 57:43–53.

Hilton C, Osborn M and Serjeant GR (1997) Psychiatric disorder in young adults in Jamaica. *International Journal of Social Psychiatry* 43:257–68.

Holman CF (1997) Management of the child with sickle cell disease within the school setting. *Journal of School Nursing* 13:29–34.

Hughes W and Paterson K (1997) The social model of disability and the disappearing body: towards a sociology of impairment. *Disability and Society* 12:325–40.

Hurtig AL and Park KB (1989). Adjustment and coping in adolescents with sickle cell disease. In: Whitten CF and Bertles JF (eds) *Sickle Cell Disease.* New York: New York Academy of Sciences, pp. 172–82.

Jacob E, Miaskowski C, Savedra M *et al* (2006) Changes in sleep, food intake, and activity levels during acute painful episodes in children with sickle cell disease. *Journal of Pediatric Nursing* 21:23–34.

Katz ML, Smith-Whitley K, Ruzek SB *et al* (2002) Knowledge of stroke risk, signs of stroke, and the need for stroke education among children with sickle cell disease and their caregivers. *Ethnicity and Health* 7:115–23.

King AA, Tang S, Ferguson KL *et al* (2005) An education program to increase teacher knowledge about sickle cell disease. *Journal of School Health* 75:11–14.

Koontz K, Short AD, Kalinyak K *et al* (2004) A randomized controlled pilot trial of a school intervention for children with sickle cell anaemia. *Journal of Paediatric Psychology* 29:7–17.

Lee EJ, Phoenix D, Brown W *et al* (1997) A comparison study of children with sickle cell disease and their non-diseased siblings on hopelessness, depression, and perceived competence. *Journal of Advanced Nursing* 25:79–86.

MacDonald G (2003) *Using Systematic Reviews to Improve Social Care.* London: Social Care Institute for Excellence (SCIE Reports: No. 4).

Mador JA and Smith DH (1989) The psychological adaptation of adolescences with cystic-fibrosis: the review of the literature. *Journal of Adolescent Health Care* 10:136–42.

Maikler VE, Broome ME, Bailey P *et al* (2001) Childrens' and adolescents' use of diaries for sickle cell pain. *Journal of the Society of Pediatric Nurses* 6:161–70.

Maxwell K, Streetly A and Bevan D (1999) Experience of hospital care and treatment seeking for pain from sickle cell disease: qualitative study. *BMJ* 318:1585–90.

Midence K and Elander J (1994) *Sickle Cell Disease: a psychological approach.* Oxford: Radcliffe Publishing.

Midence K, Davies S and Fuggle P (1992) Courage in the face of crisis: sickle cell disease. *Nursing Times* 88(22):46–8.

Midence K, Fuggle P and Davies SC (1993) Psychosocial aspects of sickle cell disease (SCD) in childhood and adolescence: a review. *British Journal of Clinical Psychology* 32:271–80.

Midence K, McManus C, Fuggle P *et al* (1996) Psychological adjustment and family functioning in a group of British children with sickle cell disease: preliminary empirical findings and a meta-analysis. *British Journal of Clinical Psychology* 35:439–50.

Morgan S and Jackson J (1986) Psychological and social concomitants of sickle cell anemia in adolescents. *Journal of Pediatric Psychology* 11:429–39.

Murray N and May A (1998) Painful crises in sickle cell disease: patients' perspectives. *BMJ* 297:452–54.

Nash KB (1989) Self-help groups: an empowerment vehicle for sickle cell disease patients and their families. *Social Work with Groups* 12:81–97.

Nettles AL (1994) Scholastic performance of children with sickle cell disease. In: Nash KB (ed) *Psychosocial Aspects of Sickle Cell Disease*. New York: The Haworth Press, pp. 123–40.

Nettleton S (2006) *The Sociology of Health and Illness*. Second Edition. Cambridge: Polity Press.

Noll RB, Ris MD, Davies WH *et al* (1992) Social interactions between children with cancer or sickle cell disease and their peers: teacher ratings. *Journal of Developmental and Behavioural Pediatrics* 13:187–93.

Noll RB, Vannatta K, Koontz K *et al* (1996) Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development* 67:423–36.

Oliver M (1990) *The Politics of Disablement*. London: MacMillan.

Palermo TM, Witherspoon D, Valenzuela D *et al* (2004) Development and validation of the child activity limitations interview: a measure of pain-related functional impairment in school-age children and adolescents. *Pain* 109:461–70.

Papadopoulos I, Tilki M and Lees S (2004) Promoting cultural competence in health care through a research-based intervention in the UK. *Diversity in Health and Social Care* 1:107–16.

Peterson CC, Palermo TM and Swift E (2005) Assessment of psycho-educational needs in a clinical sample of children with sickle cell disease. *Children's Health Care* 34(2):133–48.

Pinckney RB and Stuart GW (2004) Adjustment difficulties of adolescents with sickle cell disease. *Journal of Child and Adolescent Psychiatric Nursing* 17:5–12.

Popay J and Roen K (2003) *Using Evidence from Diverse Research Designs*. SCIE Reports: No. 3. London: Social Care Institute for Excellence.

Richard HW and Burlew AK (1997) Academic performance among children with sickle cell disease: setting minimum standards for comparison groups. *Psychological Reports* 81:27–34.

Robinson R (1999) There is no shame in pain: coping and functional ability in adolescents with sickle cell disease. *Journal of Black Psychology* 25:336–55.

Rodrigue JR, Streisand R, Banko C *et al* (1996) Social functioning, peer relations, and internalizing and externalizing problems among youth with sickle cell disease. *Children's Health Care* 25:37–56.

Royal, C, Headings, V, Molnar, E *et al* (1995) Resilience in siblings of children with sickle cell disease. *Journal of Genetic Counseling* 4 (3): 199–217.

Samanta A, Samanta J, Johnson M *et al* (2005) Rheumatoid arthritis in minority ethnic groups: patterns of disease, clinical and sociocultural features among British South Asians. *Diversity in Health and Social Care* 2:99–118.

Schatz J (2004) Academic attainment in children with sickle cell disease. *Journal of Pediatric Psychology* 29:627–33.

Schatz J, Brown RT, Lambert R *et al* (2001) Poor school and cognitive functioning with sickle cell disease and silent cerebral infarcts. *Neurology* 56:1109–11.

Sellick C and Howell D (2003) *Innovative, Tried and Tested: a review of good practice in fostering*. London: Social Care Institute for Excellence (SCIE Knowledge Reviews: No. 4).

Serjeant GR (2001) Historical review: the emerging understanding of sickle cell disease. *British Journal of Haematology* 112:3–18.

Shakespeare T (1995) Back to the future? New genetics and disabled people. *Critical Social Policy* 15:22–35.

Shapiro BS, Dinges DF and Orne EC (1995) Home management of sickle cell-related pain in children and adolescents: natural history and impact on school attendance. *Pain* 61:139–44.

Social Care Institute for Excellence (2007) *What is a SCIE Knowledge Review?* www.scie.org.uk/publications/ knowledgereviews/index.asp (accessed 1 March 2008).

Swain J, Finkelstein V, French S *et al* (2004) *Disabling Barriers: enabling environments*. London: Sage.

Swain NF, Mitchell MJ and Powers SW (2006) Pain management of sickle cell disease. In: Brown RT (ed) *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: a biopsychosocial approach*. New York: Oxford University Press, pp. 514–30.

Taylor C (1994) *Multiculturalism: examining the politics of recognition*. Princeton: Princeton University Press.

Thomas VJ and Taylor LM (2002) The psychosocial experience of people with sickle cell disease and its impact on quality of life: qualitative findings from focus groups. *British Journal of Health Psychology* 7:345–63.

Thomas VJ, Hambleton I and Sergeant GR (2001) Psychological distress and coping in sickle cell disease: comparison of British and Jamaican attitudes. *Ethnicity and Health* 6:129–36.

Turner B (1996) *The Body and Society,* second edition. London: Sage

Wilkinson R (1996) *Unhealthy Societies.* London: Routledge.

Williams C (2000) Doing health, doing gender: teenagers, diabetes and asthma. *Social Science and Medicine* 50:387–96.

Wilson RE, Krishnamurti L and Kamat D (2003) Management of sickle cell disease in primary care. *Clinical Pediatrics* 42:753–61.

Wjst M, Roell G, Dold S *et al* (1996) Psychosocial characteristics of asthma. *Journal of Clinical Epidemiology* 49:461–6.

CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Dr Simon M Dyson, Unit for the Social Study of Thalassaemia and Sickle Cell, De Montfort University, Leicester LE1 9BH, UK. Tel: +44 (0)116 257 7751 ; email: sdyson@dmu.ac.uk; website: www.tascunit.com

Appendix 1: Knowledge review form

Author/s	
Title	
Type of publication	
Location and length of the study	
Aims and objectives	
Author's key words	
Methodology	
• sampling	
• measures	
• tools	
Main findings	
Author's conclusion	
Reviewer's notes	
Material rated for relevance, (A, B, C, D, E)	
Code for rating: A, very relevant to the research questions; B, relevant; C, partially relevant; D, of little relevance; E: not at all relevant	