Journal of Public Health | Vol. 34, No. 4, pp. 570–576 | doi:10.1093/pubmed/fds035 | Advance Access Publication 31 May 2012

Trends in hospital admissions for sickle cell disease in England, 2001/02–2009/10

Ghida AlJuburi[1], Anthony A. Laverty[1], Stuart A. Green[2], Karen J. Phekoo[2], Ricky Banarsee[3], N.V. Ogo Okoye[3], Derek Bell[2], Azeem Majeed[1]

[1]Department of Primary Care and Public Health, Imperial College London, London W6 8RP, UK
[2]NIHR CLAHRC for Northwest London, Imperial College London, London SW10 9NH, UK
[3]Department of Public Health and Applied Research Unit, NHS Brent, London HA0 4UZ, UK
Address correspondence to Ghida AlJuburi, E-mail: g.aljuburi07@imperial.ac.uk

ABSTRACT

Background Sickle cell disease (SCD) is a rising cause of mortality and morbidity in England and consequently an important policy issue for the National Health Service. There has been no previous study that has examined SCD admission rates in England.

Methods Data from Hospital Episode Statistics were analysed for all hospital episodes (2001/10) in England with a primary diagnosis of sickle cell anaemia with crisis (D57.0) or without crisis (D57.1). Secondary and tertiary diagnoses were examined among those patients admitted with either of these codes as their primary diagnosis.

Results The overall SCD admission rate per 100 000 has risen from 21.2 in 2001/02 to 33.5 in 2009/10, a rise of over 50%. London accounts for 74.9% of all SCD admissions in England. 57.9% of patients admitted are discharged within 24 h. The largest rise in admission rates was seen among males aged 40–49 years where admission rates per 100 000 increased from 7.6 to 26.8 over the study period.

Conclusions Our data show that SCD admissions are rising in England, particularly in London. Over half of patients admitted with SCD were discharged within 24 h, suggesting that some of these admissions could be prevented through better ambulatory care of patients.

Keywords chronic disease, management and policy, public health

Introduction

Sickle cell disease (SCD) is a group of inherited blood disorders in which red blood cells are abnormally formed. The abnormal cells break down causing anaemia and can also cause severe complications requiring frequent hospitalization, as well as reducing the quality of life and life expectancy. SCD affects millions of people around the world and is particularly common amongst populations originating from Africa and the Caribbean.[1] SCD is now the fastest growing and most common genetic disorder in England[2] with ~12 500 people living with the condition in the UK and 240 000 SCD trait carriers.[3] SCD is also a common reason for hospital admissions.[4,5]

Although the majority of health care for patients with SCD should be occurring in ambulatory and primary care settings, the hallmark of SCD, acute painful episodes also known as vaso-occlusive crisis, is often the reason for repeat admissions into hospital.[6] SCD is less common than chronic diseases such as cardiovascular disease, diabetes and cancer, but its high hospital utilization make the disease important from a health policy perspective.[7–9] Thus, the National Health Service (NHS) should be closely

Ghida AlJuburi, PhD Student
Anthony A. Laverty, Research Assistant
Stuart A. Green, Public Health Research Fellow
Karen J. Phekoo, Lead for Chronic Care
Ricky Banarsee, Director of Applied Research and West London Primary Care Consortium
N.V. Ogo Okoye, Head of Public Health Delivery
Derek Bell, Professor of Acute Medicine
Azeem Majeed, Professor of Primary Care

monitoring pathways of care including hospital utilization of patients with SCD.

Little data exist in England about the healthcare utilization of SCD patients. Data on hospital admissions in England for SCD can provide information about the impact of SCD on the NHS and would also be of value to clinicians, commissioners and healthcare planners. Such data could also highlight disease-specific trends. The aim of this study was to investigate trends in the rates of hospital admissions in England for SCD and to determine geographic variations. The study period covered 2001/02–2009/10. We used data from the Hospital Episodes Statistics (HES) database, which provides data on all NHS hospital admissions in England.[10] HES have been collected since 1987 by the Department of Health.[11]

Methods

We obtained data from the national HES database from April 2001 to April 2010. HES is the national administrative database for hospital activity in England and contains data on all admissions and outpatient appointments in the NHS, including patients whose treatment is funded by the NHS but performed in private hospitals.[12] HES data contains details on the diagnoses of every patient admitted to an NHS hospital in England, which are coded using the International Classification of Diseases version 10. Patients can be coded as having up to 20 different diagnoses. This analysis included patients with a primary diagnosis of 'sickle cell anaemia with crisis' (D57.0) or 'sickle cell anaemia without crisis' (D57.1). Primary diagnoses correspond to the main reason the patient was admitted to hospital. Secondary and tertiary diagnoses were examined among those patients admitted with SCD as their primary reason for admission.

Patients may be under the care of different consultants during their stay in hospital, and each of these is known as a 'finished consultant episode'. All data were collected related to hospital admissions. Different hospital episodes were aggregated into hospital spells (i.e. admissions to hospital) using a method recommended by the NHS Information Centre, based on patient identifying information, their dates of admission and discharge.[13]

Data on admissions were broken down by age (<1-year old, 1–9, 10–19, 20–29, 30–39, 40–49 years and >50 years old), sex and Strategic Health Authority and Primary Care Trust (PCT). The admission rates were sex- and age standardized. Less than 1-year old was included as a category in its own right to reflect concern over potentially high admission rates in this group and in line with previous work.[7] As London accounts for the majority of the SCD cases in England, admission rates by PCT are presented only for London due to small numbers of admission in other PCTs. Denominator data for population estimates which were used to calculate rates were obtained from the Office for National Statistics.[14] All analyses were conducted using Stata, v. 10.0.

Results

Figure 1 and Table 1 show the overall admission rates for SCD as a primary diagnosis from 2001/02 to 2009/10. From Table 1 we can see that the overall admission rate per 100 000 population has risen from 21.2 per 100 000 in 2001/02 to 33.5 per 100 000 in 2009/10. This represents a rise of >50% in the admission rate from 2001/02 levels, with a consistent year-on-year rise with the exception of between 2002/03 and 2003/04.

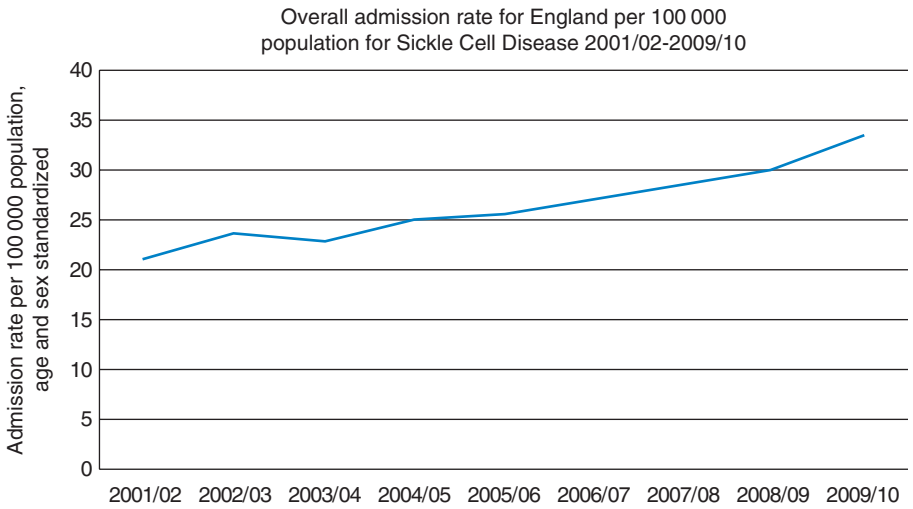

Fig. 1 Trends in admissions for sickle cell disease in England, 2001/02–2009/10.

Table 1 Age- and sex-specific admission rates per 100 000 population in England for SCD as a primary diagnosis 2001/02–2009/10

Age (years)	*Year*								
	2001/02	*2002/03*	*2003/04*	*2004/05*	*2005/06*	*2006/07*	*2007/08*	*2008/09*	*2009/10*
Men overall	20.7	24.1	24.1	25.4	25.9	28.5	31.3	32.7	35.1
<1	8.8	6.7	7.1	4.6	12.6	16.1	16.7	15.2	14.7
1–9	18.6	21.2	21.5	24.9	22.7	27.8	37.1	41.2	45.5
10–19	24.9	30.6	30.0	35.8	37.8	39.2	44.6	49.9	55.6
20–29	50.0	49.7	54.8	57.1	57.4	70.5	65.0	64.7	68.6
30–39	44.3	54.3	47.7	44.2	39.3	37.8	42.8	41.9	46.8
40–49	7.6	13.7	16.0	17.3	23.5	24.1	28.1	29.0	26.8
>50	1.6	1.4	1.6	2.3	2.3	2.1	2.7	2.8	3.2
Women overall	21.6	23.3	21.7	24.6	25.2	25.6	26.1	27.6	31.9
<1	7.3	7.0	7.9	5.2	12.8	11.9	10.9	13.2	10.8
10–9	12.6	18.5	17.7	20.3	23.0	23.5	26.1	36.5	42.2
10–19	29.1	36.3	31.9	40.3	41.8	47.3	48.5	51.2	56.4
20–29	32.4	35.4	38.0	44.6	51.9	50.9	52.1	52.4	57.9
30–39	52.4	50.1	41.2	41.7	41.4	36.6	35.7	37.0	45.3
40–49	25.4	24.5	25.9	28.0	22.1	25.7	26.0	24.7	29.2
>50	3.4	4.0	3.8	4.9	4.5	4.2	3.9	4.0	5.1
Total	21.2	23.7	22.9	25.0	25.6	27.0	28.7	30.1	33.5

This rise in admission rates has occurred in every age and sex group with the exception of women aged 30–39 years, whose admission rate per 100 000 population declined from 52.4 to 45.3 over the time period. (Table 1) The largest rise in admission rates was seen amongst men aged between 40 and 49 years old, where admission rates per 100 000 population increased from 7.6 to 26.8 over the time period (Table 1).

There were 16 558 admissions for SCD in England in 2009/10 and 8488 (51.3%) of these were men (Table 2). The admission rate per 100 000 population in this period was slightly higher in men than for women, 35.1 compared with 31.9 (Table 1). The highest admission rates in 2009/10 were amongst men aged 20–29 at 68.6 per 100 000 population (Table 1). The lowest rates were amongst people over 50 years old at 3.2 per 100 000 population for men and 5.1 per 100 000 for women (Table 1).

London accounted for almost three quarters of all SCD admissions in England (74.9% of all admissions nationally, data not shown). The highest admission rate was in City and Hackney Teaching PCT at 837.4 per 100 000 population. This rate is over twice that of the next highest PCT, Newham at 388.1 per 100 000 population (Supplementary data, Figure A). The map demonstrates geographical heterogeneity between boroughs with a clustering of boroughs with some of the highest admissions occurring in City, Hackney, Newham, Haringey, Waltham Forest and Islington (Fig. 2).

Table 2 Age and sex breakdown of crisis and non-crisis primary diagnosis, England 2009/10

Age (years)	*Sickle cell crisis (%)*	*Sickle cell non-crisis (%)*	*Total*
Men (overall)	4509 (53.1)	3979 (46.9)	8488
<1	34 (68.0)	16 (32.0)	50
1–9	478 (38.1)	777 (61.9)	1255
10–19	855 (47.4)	948 (52.6)	1803
20–29	1554 (62.8)	919 (37.2)	2473
30––39	983 (60.7)	637 (39.3)	1620
40–49	481 (47.2)	539 (52.8)	1020
50+	124 (46.4)	143 (53.6)	267
Women (overall)	8572 (51.8)	7986 (48.2)	16558
<1	17 (48.6)	18 (51.4)	35
1–9	479 (43.0)	634 (57.0)	1113
10–19	891 (51.3)	847 (48.7)	1738
20–29	1260 (62.9)	744 (37.1)	2004
30–39	787 (50.2)	780 (49.8)	1567
40–49	482 (42.7)	648 (57.3)	1130
50+	147 (30.4)	336 (69.6)	483
Total number overall	4063 (50.3)	4007 (49.7)	8070

Table 3 shows the most common secondary and tertiary diagnoses for those admitted with SCD as the primary diagnosis. The most common additional diagnostic codes were for respiratory conditions including lower respiratory tract

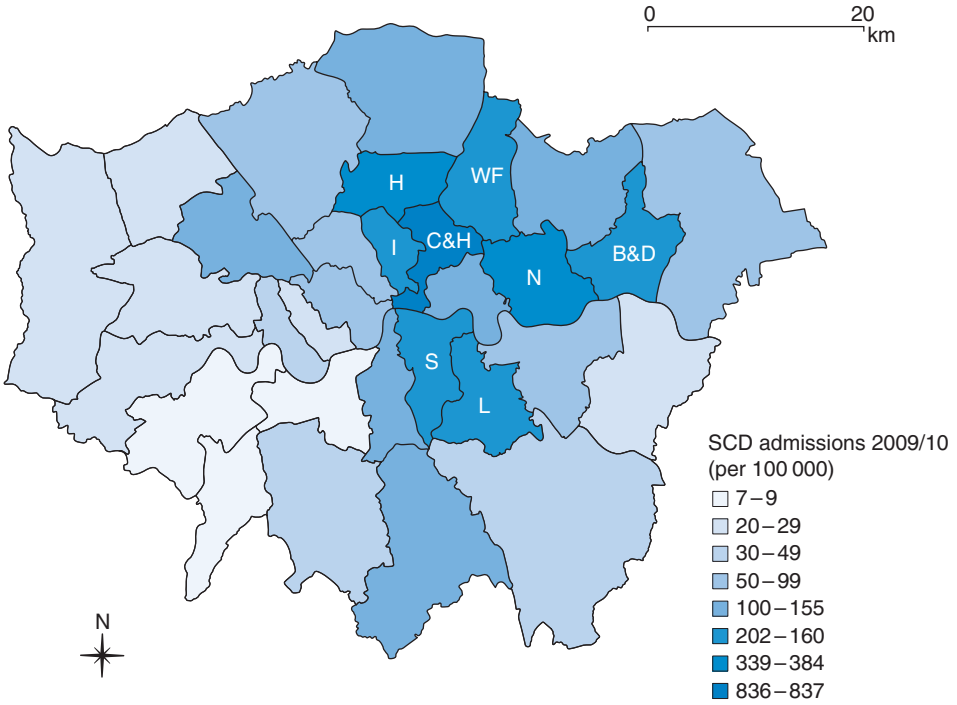

Fig. 2 Admission rate for SCD per 100 000 by PCTs, London, 2009/10; Top 8 boroughs indicated: City and Hackney (C&H), Newham (N), Haringey (H) Islington (I), Barking and Dagenham (B&D), Lewisham (L), Waltham Forest (WF), Southwark (S) in descending order of admissions.

infection, lobar pneumonia and asthma, followed by vaso-occlusive conditions such as occlusion and stenosis of middle cerebral artery, Moyamoya disease, hemiplegia and sequelae of stroke (not specified as haemorrhage or infarction).

Table 2 shows the breakdown of crisis and non-crises admissions in 2009/10. Slightly over half of all admissions (50.3%) were for a sickle cell crisis, and those in the age group of 20–29 years had a higher proportion of crisis admissions than other groups (62.8 and 62.9% for men and women, respectively). The lowest proportion of crisis admissions was in women aged over 50 (30.4%).

57.9% of all patients were discharged within 24 h of being admitted to hospital, while only 15.4% of admissions stayed for longer than a week. The largest proportion of patients discharged on the same day was for those aged over 50 years old, at 72.1% (data not shown).

Discussion

Main finding of this study

This is the first national study on trends for hospital admissions rates for SCD using HES data in England. Our data have four main findings: (i) the number of admissions due to SCD has increased substantially over the study period (2001/10); (ii) the majority of admissions are from London; (iii) most admissions were discharged within 24 h and (iv) there has been an increase in the number of admissions of middle-aged men.

What is already known on this topic

Our data show an increase of >50% in SCD admissions. This will be due to a number of factors, the most important of which is likely to be an increased prevalence of SCD in England through domestic growth of the current at-risk population and population migration from countries where SCD is common.[15]

A previous study on the national implementation of newborn screening in England showed an increased number of children identified with SCD in some areas. The authors of this study concluded that past under-ascertainment of cases may have led to under-estimation of the needs of people with SCD. Under-ascertainment of SCD cases may also have contributed to increased infant mortality in urban areas because babies were at risk of dying without a diagnosis of SCD being made and appropriate management started.[16]

The significant migration of people from the West Indies, Africa and Asia also partially accounts for the increasing incidence and prevalence of SCD in England. Some studies suggest that 6% of the population (in England) and ~10% of all births are at risk for haemoglobinopathy disorders.[17] With current trends in at-risk population migration into the

Table 3 Secondary and tertiary diagnoses among those with SCD as a primary diagnosis in NHS Hospitals, England, 2009/10

	Number (% of 2009/10 total)
Top 10 secondary diagnoses	
Acute lower respiratory tract infection	310 (1.9)
Chemotherapy	223 (1.3)
Asthma	187 (1.1)
Urinary tract infection	133 (0.8)
Lobar pneumonia	128 (0.8)
Naevi and melanomas	115 (0.7)
Occlusion and stenosis of middle cerebral artery	104 (0.6)
Moyamoya disease	96 (0.6)
Essential hypertension	91 (0.5)
Chest pain	88 (0.5)
Top 10 tertiary diagnoses	
Asthma	89 (0.5)
Sequelae of stroke, not specified as haemorrhage or infarction	64 (0.4)
Priapism	59 (0.4)
Dorsalgia	57 (0.3)
Naevi and melanomas	54 (0.3)
Acute lower respiratory tract infection	54 (0.3)
Hemiplegia	53 (0.3)
Essential hypertension	47 (0.3)
Vitamin D deficiency	42 (0.3)
Hyposplenism	41 (0.2)

country and continuing growth in the domestic at-risk population, these conditions will become even more common over the next decade.[18] Platt *et al.*[19] also explained that increases in prevalence are due to an increase in life expectancy of patients living with sickle cell through improved secondary and tertiary prevention, including improving the management of risk factors associated with haemoglobinopathies; and through earlier detection and management of disease-related complications.

The increases in admissions for SCD may also be due to a drop in the threshold for admission of patients with SCD, through greater recognition of the importance of SCD crisis, or through patients being discharged earlier and being readmitted more frequently for the same episode of illness.[20]

Studies from the USA have also shown readmission as an important contributor to rising rates of admissions in patients with SCD.[21] This may also raise issues of how well hospitals are managing these patients,[22] and emphasizes the importance of good discharge planning for these patients which may minimize the risk of hospital readmission. Good discharge planning is the process that ensures strong and quality links between hospitals, primary and community care services and patients and their carers. Effective discharge planning for those with SCD can support the continuity of health care for a patient as it links treatment received in the hospital to post-discharge care received in the community.

A study conducted at King's College Hospital showed that there has been a decrease in overnight admission rates for King's patients with SCD over the last 50 years. This is due to better disease management and better discharge planning. The number of at-risk people served at King's College Hospital has not decreased but the admissions have dropped from 111 admissions per 100 SCD patient-years in 1960–1979 to 41 in 2008–2009. The study reported that this decrease is particularly accounted for by better acute pain management and transfusions. This includes the use of hydroxyurea (a chemotherapeutic agent), increased community support, increased use of oral analgesia and improved parental education about the management of acute pain at home.[23–26] The study also reported that admission to hospital for elective blood transfusion was formerly the second most common reason for SCD admission but fell from 213 admissions to 1 over the study period. Elective transfusions are still an important aspect of care for SCD but these have been largely moved to ambulatory settings.[23,27]

SCD is still one of the most common reasons to be admitted to hospital and SCD also has one of the highest rates of multiple admissions for individual patients. The distribution of SCD in London also shows that 80% of all admissions are from people living in the most deprived areas of city.[4,5,28] Our finding that the majority of SCD admissions are discharged within 24 h was also found in another study that was conducted in the London Borough of Brent which showed that 36% of SCD patient admissions in Brent resulted in a length of stay of <2 days and that 74% of total bed days are associated with patients with multiple admissions.[28]

Limitations of this study

The strength of our study is in its comprehensiveness in that it covers all NHS hospital admissions in England. Our data have the weaknesses associated with missing, inaccurate or incomplete routine data, such as incorrect hospital diagnoses and coding. However, the advent of diagnosis-based payment of hospitals has accelerated improvement in the data quality. We used primary diagnosis to identify admissions from SCD, and 87.2% of primary diagnoses for hospital admissions in England are now coded correctly.[29] We did not examine readmissions and multiple admissions in the same patient, which could have provided further valuable insight into patterns of SCD admissions.

We also did not examine the mortality data linked to hospital episodes,[3] which would have given information of deaths associated with SCD hospital admissions. However, as this was a study about the burden of admissions, re-admissions and mortality data were not relevant to this study.

What this study adds

We examined trends in hospital admissions associated with SCD in England. We found that between 1999/2000 and 2009/10, the rate of hospital admissions in England has increased for SCD; that London accounts for the majority of admissions in England and that majority of these hospitalizations are short stay. These data show that SCD is a growing concern in England and provides a basis to continue further investigation into explaining such trends. The study also highlighted that the majority of patients admitted with SCD were discharged within 24 h. These admissions could potentially be prevented through better ambulatory and community care of patients, including better care in emergency departments, and this is an area that PCTs with a high prevalence of SCD should consider investigating.

Supplementary data

Supplementary data are available at the *Journal of Public Health* online.

Acknowledgements

Imperial College London is grateful for support from the NIHR Biomedical Research Centre scheme and the Imperial Centre for Patient Safety and Service Quality.

Funding

This work was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Northwest London, Brent PCT and Imperial College London.

Conflict of interest

This article presents independent research commissioned by the National Institute for Health Research (NIHR) under the Collaborations for Leadership in Applied Health Research and Care (CLAHRC) programme for North West London. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

References

1 Weatherall D, Hofman K, Rodgers G *et al* A case for developing north-south partnerships for research in sickle cell disease. *Blood* 2005;**105**:921–3.

2 NHS Sickle Cell and Thalassaemia Screening Programmes. *Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care*, 2nd edn. Sickle Cell Society, 2010.

3 Department of Health. National service framework for long-term conditions. Department of Health, 2005.

4 London Health Observatory. Analysis of frequent hospital users, by PCT 2003/4 [Online]. 2006. http://www.lho.org.uk/viewResource.aspx?id=10286 (September 2011, date last accessed).

5 Lucas SB, Mason DG, Mason M *et al* A sickle crisis? A report of the National Confidential Enquiry into Patient Outcome and Death, 2008. http://www.ncepod.org.uk/2008report1/Downloads/Sickle_report.pdf#search='sicklecell'.

6 Aisiku IP, Smith WR, McCLish DK *et al* Comparisons of high versus low emergency department utilizers in sickle cell disease. *Ann Emerg Med* 2009;**53(5)**:587–93.

7 Epstein K, Yuen E, Riggio JM *et al* Utilization of the office, hospital and emergency department for adult sickle cell patients: a five year study. *J Natl Med Assoc* 2006;**98(7)**:1109–13.

8 Bilenker JH, Weller WE, Shaffer TJ *et al* The costs of children who have sickle cell anemia: preparing for managed care. *J Pediatr Hematol Oncol* 1998;**20**:528–33.

9 Davis H, Moore RM Jr, Gergen PJ. Cost of hospitalizations associated with sickle cell disease in the United States. *Public Health Rep* 1997;**112**:40–3.

10 Department of Health. *An Introduction to HES, Overview of the Hosptial Episode Statistics System*. London: Department of Health, 1999.

11 Majeed A. Hospital admissions data: why are they collected? *Clin Manag* 1998;**7**:160–6.

12 Hospital Episode Statistics Online. http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=87 (12 September 2011, date last accessed).

13 The Health and Social Care Information Centre. The information centre: methods for construction of provider spells. http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=1072 (21 September 2011, date last accessed).

14 ONS population estimates. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-50032 (28 September 2011, date last accessed).

15 World Health Organization. Sickle cell anaemia report by the secretariat, 2006, A59/9.

16 Streetly A, Latinovic R, Hall K *et al* Implementation of universal newborn bloodspot screening for sickle cell disease and other clinically significant haemoglobinopathies in England: screening results for 2005 to 2007. *J Clin Pathol* 2009;**62**:26–30.

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

18 Streetly A, Clarke M, Downing M *et al* Implementation of the newborn screening programme for sickle cell disease in England: results for 2003–2005. *J Med Screen* 2008;**15(1)**:9–13.

19 Platt OS, Brambilla DJ, Rosse WF *et al* Mortality in sickle cell disease: life expectancy and risk factors for early death. *N Engl J Med* 2008;**330**:1639–44.

20 Patel H, Bell D, Molokhia M *et al* Trends in hospital admissions for adverse drug reactions in England: analysis of national hospital episode statistics 1998–2005. *BMC Clin Pharmacol* 2007;**25(7)**:9.

21 Ballas SK, Lusardi M. Hospital readmission for adult acute sickle cell painful episodes: frequency, etiology, and prognostic significance. *Am J Hematol* 2005;**79**:17–25.

22 Maxwell K, Streetly A, Bevan D. Experiences of hospital care and treatment seeking for pain from sickle cell disease: qualitative study. *BMJ* 1999;**318**:1585.

23 Day TG, Thein SW, Drasar E *et al* Changing pattern of hospital admissions of children with sickle cell disease over the last 50 years. *J Pediatr Hematol Oncol* 2011;**33(7)**:491–495.

24 Halsey C, Roberts IA. The role of hydroxyurea in sickle cell disease. *Br J Hematol* 2003;**120**:177–86.

25 Jacobson SJ, Kopecky EA, Joshi P *et al* Randomised trial of oral morphine for painful episodes of sickle-cell disease in children. *Lancet* 1997;**350**:1358–61.

26 Mahat G, Scoloveno MA, Donnelly CB. Written educational materials for families of chronically ill children. *J Am Acad Nurse Pract* 2007;**19**:471–6.

27 Murtaza LN, Stroud CE, Davis LR *et al* Admissions to hospital of children with sickle-cell anaemia: a study in south London. *Br Med J* 1981;**282**:1048–51.

28 Green S, AlJuburi G, Amobi C *et al* Characterising emergency admissions of patients with sickle cell crisis in NHS Brent: observational study, 2011.

29 Audit Commission. PbR data assurance framework, 2009. http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/20090827pbrdataassuranceframework0809rep.pdf.