[TASC • Unit]
Unit for the Social Study of Thalassaemia and Sickle Cell

Funders: E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Education of Minority Ethnic Pupils: Young People with Sickle Cell Disease

A team of researchers at De Montfort University, University of York and Loughborough University was funded by the Economic and Social Research Council to report on the experiences of young people with sickle cell disorders in the education system in a multi-method study between 2006 and 2011.

What is Sickle Cell Disease / Sickle Cell Disorder (SCD)?
SCD is a complex condition with major symptoms including strokes, silent strokes, chronic pain, and acute painful crises generally regarded as at, or beyond, the pain of terminal cancer. It affects all ethnic groups, though at different rates of prevalence. 1 in 7 Black African and 1 in 540 White British newborns in England carry genes associated with sickle cell.

What numbers are involved?

SCD is the most common single gene condition in England affecting 1 in 2,300 of all births. Based on this birth rate, numbers with SCD are projected to rise from 12,500 to over 20,000. Nearly one-quarter of all pupils of primary age in England are in ethnic groups at higher risk of carrying genes associated with SCD.

What is the source of evidence for this paper?
1. A survey of all local authorities in England about their response to the issue of SCD (107/150 replied).
2. A survey of 569 pupils living with SCD, from twenty different sites across England, about their experiences at school.
3. In-depth interviews with 40 young people with SCD
4. A survey of 206 schools attended by young people with SCD
5. Case studies of ten young people with SCD

What is the current position of Local Authority Children and Young Person's Services with regard to SCD?
Whilst most authorities agreed that children with SCD should be given an individual health care plan (IHCP), only 14/107 could state how many children under their jurisdiction had an IHCP and only 15/107 could even state how many children with SCD they had in their schools. Only 2/107 had any written policy on children with SCD. Thus at this level SCD as a potential issue affecting pupils is

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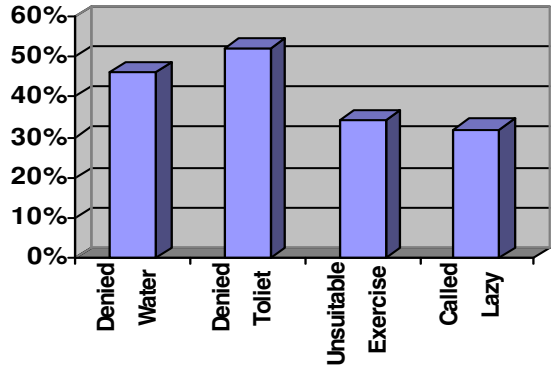
Simon Dyson, Lorraine Culley, Sue Dyson, (all De Montfort University)
Karl Atkin, University of York
Jack Demaine, Loughborough University

relatively invisible in education policy terms.

Isn't SCD only relevant for London and a few other large urban areas?
No. SCD in increasingly not confined to areas traditionally thought of as having high numbers of minority ethnic groups. This is because (1) SCD is increasingly not confined to minority ethnic groups (hence the decision of the NHS Screening Programme to screen ALL babies born in England for SCD, irrespective of ethnicity) (2) those groups predominantly affected are increasingly resident outside London. Even an authority ranked 122/150 of all local authorities in terms of numbers of Black pupils was able to report five children with SCD. Conversely, an authority covering an area deemed by the NHS to be a high prevalence area for SCD claimed (wrongly) that they had no pupils with SCD in their area.

Isn't SCD covered by the DCFS guidance on children with medical conditions in schools?
Not adequately. The guidance does not mention sickle cell explicitly. In particular because prevention does not feature explicitly in the guidance, opportunities to prevent sickle cell complications (keeping warm; being allowed to drink water in class in order to remain well-hydrated; being permitted to go to the toilet, as children with SCD cannot concentrate urine as easily; avoiding strenuous exercise, such as cross-country runs in the rain; avoiding stress) may not be highlighted to schools.

What do children with SCD say happens to them in school?
Children with SCD report not being cared for adequately at school. For example a majority of children say that they have been prevented from going to the toilet when needed; about half report that they are not permitted to drink water; about a third that they are made to take unsuitable exercise. All of these could trigger a severe sickle cell painful crisis. Furthermore, 30% say that they have been called lazy when in fact they are tired from their anaemia. These percentages represent hundreds of children with SCD reporting these experiences in school.



What about missed schooling because of SCD?
In addition to absences for other reasons, children report they miss an average of over 16 days per year with SCD-related illness, with 12% missing more than 63 sessions and a few missing hundreds of days of schooling a year.

What about the duty on schools to make provision when 15 days or more are missed?
Only around 5% say they are enabled to fully catch up lessons missed, and nearly 20% that they are not helped to catch up at all. The average reported is that they are helped to catch up about 38% of what is missed.

What do teachers know of SCD?
About 10% of parents do not tell the school the child has SCD, largely because of their concern the way the child will be treated. Whether or not the school has been told the child has SCD makes little difference to the way the child is reportedly treated at school, and in some

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instances reportedly leads to worse treatment. There is a difference between a teacher knowing a child has SCD and knowing the full implications of a child having SCD.

What do young people with SCD feel about telling others they have sickle cell?

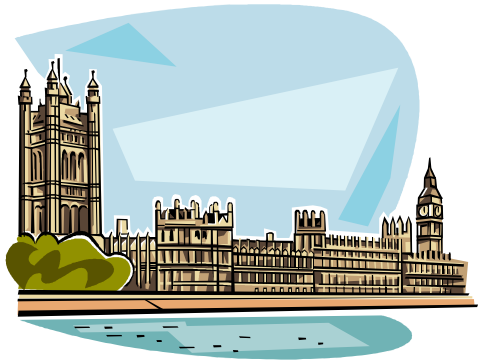
In the main young people living with sickle cell feel that their teachers should know about their SCD, but opinions about whether or not it is better for peers to know are more divided. The advantages of telling others were the hope that the information would be used to better understand what you people with SCD are going through (as long as this did not amount to being patronizing and constantly fussing over how they are); to make reasonable adjustments by putting in place preventive measures to stop young people with sickle cell becoming ill, to advocate on their behalf, to help in practical ways when this was needed, and to respond if they became ill. The disadvantages were of being bullied or taunted, of reinforcing ignorant views, of provoking over-sentimentality, but above all in drawing attention to themselves as allegedly different from their peers

How do individual schools support young people with SCD?

Less than ten per cent of schools had a specific policy for young people with SCD. Under guidance issued by the Department for Children, Families and Schools, all children with a medical condition should have an individual health care plan to support them at school. Less than half (89 of 206 schools surveyed) appeared to have individual health care plans for their student with SCD. Less than a quarter of teachers responsible for care of young people with SCD had received an in-service education to guide them in this role.

Influencing Policy

Two members of the team were invited to address the All Party Parliamentary Group on Sickle Cell and Thalassaemia (under Dianne Abbott, MP) Portcullis House, Westminster 25th March 2009, and a parliamentary report *The Social Aspects of Sickle Cell Disease and Thalassaemia in Young People* was produced.



Two members of the team were invited to address the Parliamentary Health Committee (under Kevin Barron MP) Portcullis House, Westminster 2nd November 2009.

The team was asked to brief Steve McCabe MP (Birmingham, Selly Oak) on sickle cell and education in January 2010. He then initiated a local campaign in Birmingham to try to improve the situation for young people with sickle cell at school.

Recommendations

1) The Department of Education should re-issue the *Guidance on Children with Medical Conditions at School* with a specific section on sickle cell.
2) Use this re-issue to highlight the idea of PREVENTION; stress that individual health care plans should also have sections on prevention; promote the idea that schools should AUDIT the physical and social environment of the school. By using sickle cell as the example, this could help children with other medical

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conditions where prevention is an issue.

3) Re-issue guidance on the 15 days absence leading to the requirement to make alternative provision. Stress that the guidance means ANY fifteen days not just consecutive days. Children with SCD need funded support with access to a teacher, not merely encouraged to copy up notes they may not necessarily understand. By using sickle cell as the example, this could help children with other medical conditions where intermittent absence is an issue.
4) Make available to schools and local authorities a full briefing, through workshops, on care of the child with SCD at school, outlining all the ramifications of the condition for the school experience.
5) Local authorities seem unaware of the issue of SCD. All children born in England are screened at birth for SCD. Require the Directors of Public Health to notify their Local Authority Director of Children and Young Persons of the numbers of children born each year with SCD.

Web-Site

The project has rented the domain name www.sicklecelleducation.com and has developed content to provide an information site on the project for schools with pupils who have sickle cell. The web-site became live on January 25th 2010. The site includes downloadable pdf files for use in school awareness.

Publications

Dyson, SM; Atkin, K; Culley, LA; Dyson, SE; & Evans, H (2011) Sickle cell, habitual dyspositions and fragile dispositions: young people with sickle cell at school *Sociology of Health and Illness*

Dyson, SM; Atkin, K; Culley, LA; Dyson, SE; Evans, H & Rowley, DT (2010) Disclosure and sickle cell disorder: a mixed methods study of the young person with sickle cell at school *Social Science and Medicine* 70 (12): 2036-2044.

Dyson, SM; Abuateya, H; Atkin, K; Culley, LA; Dyson, SE; and Rowley, DT (2010) Reported school experiences of young people living with sickle cell disorder in England *British Educational Research Journal* 36 (1): 125-142.

Dyson, SM; Abuateya, H; Atkin, K; Culley, LA; Dyson, SE; & Rowley, DT (2008) Local authorities and the education of young people with sickle cell disorders in England *International Studies in Sociology of Education* 18 (1) 47-60.

Abuateya, H; Atkin, K; Culley, LA; Dyson, SE and Dyson, SM (2008) Young People with Sickle Cell Disorder and Education: A Knowledge Review *Diversity in Health and Social Care* 5 (2): 123-135.

Dyson, SM; Atkin, K; Culley, LA and Dyson, SE (2007) The educational experiences of young people with sickle cell disorder: a commentary on existing literature. *Disability and Society* 22 (6): 581-594.

Further Information

The Economic and Social Research Council is the UK's leading agency for research funding and training in the social sciences
www.esrcsocietytoday.ac.uk

The Sickle Cell Society
www.sickecellsociety.org

OSCAR Organization for Sickle Cell Anaemia Research
www.oscarbirmingham.org.uk

Sickle Cell Young Stroke Survivors
www.scyss.org

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