Reported school experiences of young people living with sickle cell disorder in England
Funding
RES-000-23-1486.
Research Team

- Dr Hala Evans (nee Abuateya), Unit for the Social Study of Thalassaemia and Sickle Cell, Research Fellow
- Dr Karl Atkin, University of York
- Professor Lorraine Culley, De Montfort University, Leicester
- Professor Simon Dyson, Unit for the Social Study of Thalassaemia and Sickle Cell, Project Director
- Dr Sue Dyson, De Montfort University, Leicester
- Dr Jack Demaine, Loughborough University
Acknowledgements

- Kings College, North West London (Brent); Guys and St Thomas’s.
- Sickle Cell Society, Sickle Cell Young Stroke Survivors, OSCAR (Sandwell, Bristol, Nottingham, Leicester); Northampton, Milton Keynes, Luton, Barking, Tower Hamlets
- Hackney PCT, Newham PCT, Birmingham PCT
The Research: Phases 1-2

[1] Review of Secondary Sources
[2] Surveys:
[i] 107/150 education authorities and policies
[ii] 569 young people under 25 about their educational experiences
[iii] 200 schools attended by pupils with SCD.
The Research: Phases 3-5

[3] 50 depth, tape-recorded interviews
[4] 8-10 case studies with completion of year-long diaries and follow-up interviews.
[5] Policy Development Workshops at regional seminars
Survey of 569 Young People

- August 2007-August 2008
- 569 replies
Age of Respondents
<table>
<thead>
<tr>
<th>Race</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black Angolan</td>
<td>21</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>162</td>
</tr>
<tr>
<td>Black Congolese</td>
<td>19</td>
</tr>
<tr>
<td>Black Ghanaian</td>
<td>62</td>
</tr>
<tr>
<td>Black Nigerian</td>
<td>183</td>
</tr>
<tr>
<td>Black Sierra Leonean</td>
<td>46</td>
</tr>
<tr>
<td>Black Sudanese</td>
<td>6</td>
</tr>
<tr>
<td>Black Somali</td>
<td>6</td>
</tr>
<tr>
<td>Black Other</td>
<td>46</td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
</tr>
<tr>
<td>White English/Scottish/Welsh</td>
<td>3</td>
</tr>
<tr>
<td>Others White</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>562</td>
</tr>
</tbody>
</table>
Changing ethnic composition of Black communities in UK

- African Caribbean: 10% carriers; 0.25% SCD
- African: 25% carriers; 2% SCD
- For same size of population there will be 8 times the number with SCD in a Black African population compared to a Black Caribbean population
Stroke

- 135 out of 569 reported having had a stroke
  = 23.7%
<table>
<thead>
<tr>
<th>Number of Crises Last Year</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>113 (20%)</td>
</tr>
<tr>
<td>1</td>
<td>62 (11%)</td>
</tr>
<tr>
<td>2</td>
<td>53 (10%)</td>
</tr>
<tr>
<td>3</td>
<td>67 (12%)</td>
</tr>
<tr>
<td>4</td>
<td>37 (7%)</td>
</tr>
<tr>
<td>5</td>
<td>65 (12%)</td>
</tr>
<tr>
<td>6</td>
<td>32 (6%)</td>
</tr>
<tr>
<td>7</td>
<td>20 (4%)</td>
</tr>
<tr>
<td>8</td>
<td>11 (2%)</td>
</tr>
<tr>
<td>9</td>
<td>6 (1%)</td>
</tr>
<tr>
<td>10 or more</td>
<td>87 (16%)</td>
</tr>
</tbody>
</table>
School Days Missed per Year (Sickle cell related)

- Ranged from 0-200 days
- Average (Mean) 16.27 days (sd 25 days)
- Most frequently reported (Mode) 10 days
- 15 days: school required to make special provision if a child is absent for total of 15 days
- DCSF defines truancy: 63 sessions (half days) or 32 days = “persistent absence”
- Around 12% of our sample absent for more than 32 days (danger of being labelled truant)
School Days Missed per Absence

- 0-112 days
- Mean 7.14 days (sd 12 days)
- Most frequently reported (Mode) 2, 3 or 5 days
- Young people with SCD miss schooling but in short periods, thus never triggering the 15-day rule when schools have to make other arrangements
How Much Caught Up (%)?

[Mean = helped to catch up about 38%]
Reported Experiences in Schools

- Not Allowed Toilet: 57%
- Not Allowed Drink: 46%
- Unsuitable Exercise: 36%
- Called Lazy When Tired: 34%
Reported Triggers for Pain Crises in Schools

- Unsuitable exercise: 43%
- Hot/Cold: 54%
- Teacher: 30%
- Pupil: 25%
- Furniture: 21%
Reported reactions when child in pain

- Teacher told: 75%
- Teacher believes: 62%
- Children believe: 53%
- Teacher helps: 47%
- Painkillers: 27%
- Sent Hospital: 20%
- Collected: 59%
Reported subjects covering SCD

- Science: 23%
- Maths: 3%
- English: 3%
- Hist/Geog: 2%
- PE: 6%
- PHSE: 9%
- Art/Drama: 4%
- Assembly: 11%
Conclusion

- First national survey of young people with SCD about their experiences at school
- Extensive absences but in series of short periods so that policies for support are not triggered
- Perception of young people that they are NOT helped to catch up what they have missed
- In four key areas (toilet, water, exercise, lazy) young people are not supported and are needlessly becoming ill
- Four areas reported for over 25 years without being addressed → individual person/parent blamed
- Need for systematic policies to support young person with SCD at school
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 [ISSN 0141-1926]  
http://dx.doi.org/10.1080/01411920902878941
Further Information

For further information on this research programme, please visit:

http://www.sicklecelleducation.com

End of presentation