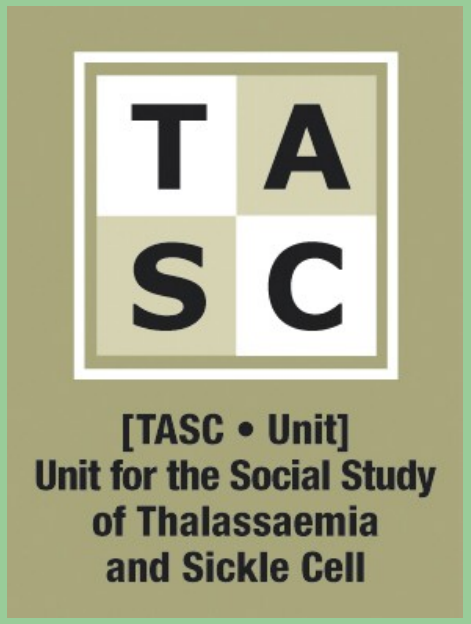
The Educational Experiences of Young People with Sickle Cell Disease: a commentary on the existing literature



Simon Dyson

Sickle Cell and Education

Lecture 1 of 6

Objectives

- To review literature on sickle cell in education
- To outline the main conceptual areas linking the issues of young people with sickle cell and education
- To provide a rationale for an empirical programme of research on sickle cell and education.

Eight Areas of Concern

- Medical Care of Children with SCD in School
- School Experience, School Attendance and Sickle Cell
- Preventive Measures and Sickle Cell
- Personal, Social and Health Education
- Sickle Cell and the School Curriculum
- Educational Policy and Sickle Cell
- Sickle Cell in the Context of Racist Discourses
- Sickle Cell in the Context of Disabling Discourses

Medical Care of Children with SCD in School

- Psychological well-being (Telfair,1994)
- Teacher confidence in dealing with SCD (Noll et al, 1992)
- Enuresis (Anionwu, 1982);
- Identifying and responding to sickle cell crises and strokes (Katz et al, 2002; Koontz et al, 2004)
- School dental, hearing and visual screening checks (Laurence et al, 2002; Savundra, 1996; National Institutes of Health, 2002).

School Experience, School Attendance and Sickle Cell

- Children with SCD take time off school for preventive health measures, medical monitoring, and clinical treatment (Black and Laws, 1986; Nettles, 1994; Shapiro et al, 1995; Zeuner et al, 1999; Gil et al, 2000);
- Report a disappointment with the lack of educational support from teachers (Fuggle et al, 1996);
- Feel that teachers write off their chances of academic success (Atkin and Ahmad, 2001).
- Teachers of children with SCD assume them to be poorly motivated, to come from an unstable family, to have drug problems or even to be HIV positive (Noll et al 1992, 1996).
- Education of teachers, school peers and parents reduces school absences in children with SCD (Koontz et al, 2004).

Preventive Measures and Sickle Cell

- Prevention of infections
- Avoidance of cold or damp conditions
- Adequate hydration and toilet breaks
- Taking moderate but avoiding strenuous exertion
- Other factors (e.g. science lab chairs)

Personal, Social and Health Education

- Confusion between trait and SCD has led both to discrimination (Stamatoyannopoulos, 1974; Bowman, 1977; Draper, 1991, Wilkie, 1993)
- Education campaigns inadvertently increasing stigma (Wailoo, 2001).
- Class discussions around reproductive rights, especially termination within PHSE

Sickle Cell and the School Curriculum

- SCD can be incorporated into the curriculum
- Maths (probability)
- Biology (genetics)
- Geography and history (the spread of the sickle cell gene with slavery)
- Arts
- A cross-curricula approach has been proposed by an education authority (ILEA, 1989).

Educational Policy and Sickle Cell

- The earliest educational policy (ILEA, 1989)
- Included advice on preventative measures; implications for pastoral work; implications for the personal and social education curriculum; implications for a cross-curricula approach to education; and a list of resources.
- With the growth in the local management of schools, it is not known to what extent current authorities have developed comparable policies.

Sickle Cell in the Context of Racist Discourses

- Alleged lack of educational commitment on the part of the student and/or their carers (Barbarin, 1994)
- Stereotypes about sexuality (Collins, 2001),
- Stereotypes of drug use (Teixiera, 2003),
- Stereotypes of laziness (Jones and Shorter-Gooden, 2003; Figueroa, 2000),
- Stereotypes of athleticism (Cashmore, 2000; Fleming, 2001).

Sickle Cell in the Context of Disabling Discourses

- People with SCD dislike being defined by their condition: called “sicklers”
- People living with SCD inappropriately blamed for school absences, poor school performance failure to complete homework – labelled as “maladaptive” (Barbarin, 1994)
- People living with SCD vulnerable to disabling views of the body: yellow eyes, delayed development
- Limits to social model of disability. Emphasis on independence as opposed to control in family care. For young black people family may be refuge and learning resource against racism.

Conclusion

- A research programme on experience of young people with sickle cell timely because:

1) Most research US not UK
2) Most research clinical not social
3) SCD in schools: chronic illness and racialization
4) Potential application of a social model of disability

Reference

- 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. [ISSN: 0968-7599] http://dx.doi.org/10.1080/09687590701560196

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Further Information

For further information on this research programme, please visit:

http://www.sicklecelleducation.com

End of presentation