Sickle Cell, Habitual Dys-positions and Fragile Dispositions: Young people with Sickle Cell at School

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Sickle Cell and Education
Lecture 5 of 6
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Research Team

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- 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
Methods

- 40 taped in-depth interviews
- 6-25 (average age 16)
- 21 female, 19 male
- 24 Black African, 15 Black Caribbean, and one British Asian
- Home (3); community centre (9); counselling centre (3); hospital outpatients (21); or at the university (2).
- Selected for variety in educational experience
Data Analysis

- Thematic analysis
- 20 themes indentified and agreed up by 5 members of the research team
- Pierre Bourdieu: French sociologist
- Used social theory to make sense of data
Pierre Bourdieu: Field

- Field: structured space for struggle for positions (like a game)
- The School
- Teacher: pupil
- Internal setting; external league tables;
- Degree of autonomy (hidden curriculum, school ethos)
Pierre Bourdieu: Capital

- Capital: economic capital
- Symbolic and Cultural capital (the ‘right’ types of knowledge, demeanour, language, taste, bodily disposition)
Homer and the ‘right’ type of knowledge

- As an example of what we mean by ‘cultural capital’ think of Homer
- Do you think of the classic Greek poet (knowledge of which might index an élite education) or of Homer Simpson?
Pierre Bourdieu: Habitus

- **Habitus**: taken-for granted practical skills for navigating particular contexts of life. [Tactics or dispositions].
- These attributes may also be **embodied** (social relations incorporated into the body which is then seen as “natural” and not deriving from society)
Embodiment

- Body is more than just a physical corporeal object
- The way we inhabit our bodies carries particular social meanings and these meanings are different in different contexts
- The body is not just ‘there’: we are embodied as a social process
Fields

- School
- Clinic (not just physical setting but clinic ‘mentality’, emphasis on self-care)
- Water, Toilet, Exercise, Warmth, Rest
Habitually Dys-positioned

- Clinic: responsibility for self-care
- School: timetables, routines, contextual expectations of active (PE, answering teacher questions) and passive (not interrupting)
G8: [...] I had to get water when I was in class. I told my teacher but she said I should have got water from the nurse at lunchtime and, and also there’s a (warning score) it says you can’t go to get a drink during class time.

(Female, 13, Black African)
“Yeah unless I would explain to them just ask and nag them then maybe, cos they kept on saying, they kept on, they said it was like a way of preparing you for secondary school, for secondary school cos we wasn’t, they thought we wasn’t allowed to go toilet during class”.

(Male, 16, Black African)
The league table of examination results. B16 (Male, 15, Black African) recounts that being granted a toilet break “depends on the teacher and the seriousness of the topic. If it is something that has to go into the GCSE results then you cannot go”
The monitoring of attendance. B7 (Male, 15, Black African) speculates why his school does not allow toilet breaks and drinks breaks: “I think I know why they don’t do that, because they’re trying to prevent truancy in the school.”
Exercise

- My teacher, I was in PE class and like he was keep on like, pushing me, pushing me, and I didn’t like much, football, and I’d tell him like I didn’t like doing and like when I was sitting out he’d come up to me ‘Stand up’ and like ‘Play the game’.

(Male, 15 years, Black Caribbean)

There's a breathless hush in the Close to-night
Ten to make and the match to win
A bumping pitch and a blinding light,
An hour to play, and the last man in.
And it's not for the sake of a ribboned coat.
Or the selfish hope of a season's fame,
But his captain's hand on his shoulder smote
"Play up! Play up! And play the game!"

(Henry Newbolt, 1897)
The sand of the desert is sodden red -
Red with the wreck of a square that broke
The gatling's jammed and the colonel dead,
And the regiment blind with dust and smoke.
The river of death has brimmed its banks,
And England's far, and Honour a name,
But the voice of a schoolboy rallies the ranks -
"Play up! Play up! And play the game!"

This is the word that year by year,
While in her place the school is set,
Every one of her sons must hear,
And none that hears it dare forget.
This they all with a joyful mind
Bear through life like a torch in flame,
And falling fling to the host behind -
"Play up! Play up! And play the game!"

(Henry Newbolt, 1897)
Bodily disposition

- Sit up straight
- Pay attention
- Don’t interrupt
- sitting up straight : achieving student
- student slouching : under-achieving student
Tired from Anaemia

- G1: [...] the teacher is ‘[Name], why is your arm on the table? Why are you so lazy?’ You know, it’s like I’m not lazy, I’m just tired. And it just got to a point where I was so tired I couldn’t be bothered to argue so I just walked out the class. And then the teacher came: ‘Why did you leave my class?’

(Female, 16, Black African)
Dys-positioned

- Dysfunctional
- Dys-positioned between the demands of the school and the demands of the clinic
Dispositions (tactics) [Tell others?]

- I think I was sick and I went in an Ambulance and it must have been a PE because I was running too much, and I was just collapsed and I could not take it and the ambulance came and they were asking a couple of questions about sickle cell. And there was someone standing next to the ambulance and listening to the conversation......

(Female, 15 years, Black African)
Dispositions (tactics) [Tell others?]

- G17: Some understood and wanted to know what sickle cell is. Others just did not care about it and were not willing to know. Some just want to know the details, while others just turn their backs. Some said, oho, now we understand why you have these yellow eyes and you are skinny. It was not nice to hear these comments.

  (Female, 16 years, Black Caribbean)
Dispositions (tactics) [Tell others?]

- [...] because some other students know that I've got sickle cell through my primary school and they're in my secondary school in my class still and they ask me what it is sometimes. And then one day they just come up to me and say 'Oh, what's sickle cell? What happens?' And stuff, and I explain, yeah. But if you tell other children that, other students that don't know, they pass it on to other people. And then it becomes, and then they call it probably something else and they give it another description

  (Female, 13 years, Black African)
Well, yeah, because it is really hard to take it in, even now I feel struggling with it. Like you try to listen, like you don’t feel alert, and your body is aching, and it is just that you don’t really learn, you cannot take it in, it is really hard. I mean it is hard in school, where school is, because of my attendance, they also put me in certain subjects, and what is it, I have like one, two, one three, like groups of, say when you do exams you can just get from C-E you cannot get higher than C. You can only receive that grade because that is what they think you are capable of, and if I have the support from whatever, I reckon I could be like in the X band which is higher than the Y band, and you got Y and Y4 and stuff like that. And I was always put in Y2, 3 are for special needs kids and stuff like that.
And I did not see myself, I am not saying level, so in that, there are kids there because they have special needs or whatever, and the teacher would not bother teaching them because they say the longer it takes to do what you lots do because I am still getting paid. It’s up to you if you want to learn. So that knocked me because I was put in that groupwork where you received Cs and Ds and Es in my exams and in my actual coursework I got As and Bs and I thought if I have the opportunity I think I would be different. Because of my attendance, because I was not in that school as much because I was sick, they just put me in that group [...] They told me of course that what I would like to do, I put into (design), that was not an interest of mine. I like child care and probably food and hygiene or something like that, but they chose that for me, just because I was ill and did not have time to sit with me and give me the nurturing I needed [...] yeah, that was one of the biggest blows in school.

(Female, 24 years, Black Caribbean)
Middle Class

- Series of international schools
- "I was out of school for a while because dad had to stop work and stay in the hospital with me"
- Wanted to try acting but expensive law training as a fallback position

Working Class

- Lack of support at school and several FE colleges
- "hopefully I want to work."
Middle Class

- HbSS (more severe?)
- With Dad at interview
- if I don’t feel well my *mum or dad* [our emphasis] will write a note for me to take in to [school].”
- Both parents in work as paid professionals

Working Class

- HbSC (less severe?)
- Interviewed with counsellor looking to protect from peer group
- Single mother of ten
- Counsellor associated his poor health with low income
School Ethos

Positive School Ethos
- Bullying effectively challenged
- Included in all school activities and trips, even trip abroad to Europe

Negative School Ethos
- Bullying not challenged and persists over entire school career
- Excluded from even local trips to the city farm.
Conclusion

- Dys-positioned between the demands of the school and the demands of the clinic
- Cultural Capital eroded
- Dispositions or tactics for navigating life at school are fragile (vulnerable to not working)
Dyson, SM; Atkin, K; Culley, LA; Dyson, SE; and Evans, H (2011) Sickle cell, habitual dyspositions and fragile dispositions and fragile dispositions: young people with sickle cell at school Sociology of Health and Illness (forthcoming)
Further Information

For further information on this research programme, please visit:

http://www.sicklecelleducation.com

End of presentation