Social Science & Medicine 70 (2010) 2036–2044

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school

Simon Martin Dyson [a,*], Karl Atkin [b], Lorraine A. Culley [a], Sue E. Dyson [a], Hala Evans [a], Dave T. Rowley [a]

[a] De Montfort University, Leicester, UK
[b] University of York, York, UK

ARTICLE INFO

Article history:
Available online 23 March 2010

Keywords:
England
Sickle cell
Education
School health
Chronic illness
Stigma
Mixed methods
Young people

ABSTRACT

Sickle cell is a leading genetic condition, both globally and in England. Little research has been conducted into the experiences of young people with sickle cell at school. A mixed methods study (May 2007–September 2008) based on 569 questionnaires and 40 taped interviews with young people living with sickle cell disorder (SCD) in England found that students with SCD are faced with a dilemma as to whether or not to disclose their sickle cell to teachers and pupils: the latent and hidden characteristics of their symptoms make it possible, in Goffmanesque terms, to "pass". However the variable and unpredictable course of sickle cell is a reminder of Goffman's notion of being "discreditable". We found that teacher or pupil knowledge that a young person has sickle cell is not statistically associated with reported better treatment of young people with SCD at school. Analysis of interviews suggests most young people favour disclosing their sickle cell status (on the basis that teachers will then know what actions to take in the face of bouts of illness and in terms of making allowances for illness or school absences). A minority disagreed because disclosure was felt to attract unwarranted attention or disabling attitudes. Attitudes to disclosing to peers were more varied: either for or against disclosure to peers, or ambivalent in that they felt a tension between acknowledging the reality of their sickle cell, and not wanting it to be a central part of their identity. Some health promotion advice appears to assume that teacher and/or peer awareness is the key to improving school experience for young people with SCD, but this is not borne out by this study. Rather a change in wider school environments is required such that young people with SCD are supported irrespective of whether they themselves foreground or play down their disabled identity.

Introduction

Sickle cell disorders (SCD) are serious inherited chronic illnesses potentially impacting on many systems of the body (Okpala, 2004). They affect 1 in 2300 of all births in England (NHS Sickle Cell and Thalassaemia Screening Programme, 2006). To date the experience of young people (children aged 4–14 and youth aged 15–25) with SCD at school remains under-researched. This paper uses mixed methods to consider the extent young people with SCD disclose their status to others in school, and to interrogate the assumption that disclosure of status improves school experience. We locate our discussion of disclosure within the work of Goffman on stigma and passing. Concluding that the data are not amenable to straightforward analysis, we suggest that the contradictions in the quantitative data are reflected in the divergent views about the merits of disclosure in the narratives of the young people themselves.

Background

Young people with SCD represent a particular case of chronic illness at school, and support offered to pupils with a chronic illness by teachers is highly variable (Lightfoot, Muhkerjee, & Sloper, 2001). Teachers need to provide specific input to catch up absences (Lightfoot, Wright, & Sloper, 1999); support students with chronic illnesses in their relations with peers (Mukherjee, Lightfoot, & Sloper, 2000); and modify the school environment to prevent episodes of illness (Ciutto et al., 2006).

It is regarded as rational and self-explanatory that teachers need to understand the child's chronic illness (Cunningham & Wodrich, 2006), and indeed dominant advice about young people with SCD at school is the rationalist notion that health promotion will ensure

* Corresponding author. Unit for the Social Study of Thalassaemia and Sickle Cell, Room 1.27 Hawthorn Building, De Montfort University, Leicester LE1 9BH, UK. Tel.: +44 116 257 7751.
E-mail address: sdyson@dmu.ac.uk (S.M. Dyson).

0277-9536/$ – see front matter © 2010 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2010.03.010

that "affected children are not bullied or stigmatised" (Hogg & Modell, 1998: 6). In this paper we particularly consider the dilemma facing young people with SCD as to whether or not to reveal their status to peers or school staff. In situations where stigma may characterize a relationship, but where the person has the possibility of hiding the potentially "discreditable" aspect of themselves, Goffman (1968) suggests the person has two strategies available. One is "covering": to minimise the social effect of the situation. The other is "passing": the person with SCD passing themselves off to others as someone without sickle cell. This strategy is one that is plausibly available to a student with SCD because physical signs are often minimal (yellowing of eyes or delayed puberty); painful sickle cell crises occur only intermittently; minor painful crises could be masked; and leg ulcers could be hidden from others. In short, sickle cell is often concealable. Yet people living with SCD are equally "discreditable" (Goffman, 1968: 57). Like the chronic headache that is one of SCD's myriad manifestations, it is a "socially invisible" disease (Lonardi, 2007). But invisibility is not only an attribute, it is "in part a choice of activity and context, in part […] the untrained eye and the disbelief of others" (Lingsom, 2008: 13). Young people who have SCD, and attempt to conceal it, could at any time be revealed to others. They may undergo a sickle cell painful crisis, and an ambulance may be called. Likewise, they may suffer strokes and, if these affect speech, bodily disposition or gait, their condition could be similarly displayed to others. Somatic signs could be sufficient to be noticed, and our interviewees endured taunts from peers of "yellow eyes", "skinny" and "slowcoach". Moreover, Noll et al. (1996) have suggested that where "difference" is constructed by the teacher of the young person with SCD without access to the specific label of sickle cell, then other stigmatizing labels (HIV, drug abuse, dysfunctional family) are applied. A major life strategy for living with their highly variable condition of SCD is to try to avoid being engulfed by the illness and to strive to achieve normalcy (Atkin & Ahmad, 2001). As such, attempts to live positively with their condition by engaging in preventive measures (drinking plenty of water, wearing outdoor clothing indoors to keep warm, avoiding strenuous exercise) may also mark them apart from peers in ways that attract unwanted attention.

Goffman also introduces the notion of the "own and the wise". The own are people living with the condition who come to the fore as spokespeople for the cause. The wise are close significant others of the person living with SCD, who understand sufficient of the insider knowledge of the experience to be willing and able to advocate on behalf of that person. It is possible that close school friends could fulfil this role of the "wise". One US study found a specific whole school educational input on sickle cell promoted school inclusion of young people with SCD by virtue of peers being prepared to "look out for" the young person with SCD (Koontz, Short, Kalinyak, & Noll, 2004).

Meanwhile, some authors have sought to refine the original formulation of passing. Renfrew (2004), for example, suggests that passing has potentially negative consequences, and that masking a central identity can have emotional costs. But an analysis of passing has, along with Goffman's work itself, fallen from favour in the face of implied critiques from disability rights authors (Oliver, 1990). Such perspectives favour a challenge to disabling physical and social environments, rather than restricting the focus to the symbolic interaction of face-to-face encounters that (it is presumed by its critics) subtly reinforces the prevailing and discriminatory norms of body, psyche and life trajectory. By contrast, Goffman himself emphasized that "a language of relationships, not attributes, is really needed" (Goffman, 1968: 13). Part of these relationships in educational contexts is to struggle with disabling physical and social environments at one and the same time as negotiating identities (Low, 1996). But in this respect few studies have sought to identify how stigma is enacted in the context of social inequalities (Link & Phelan, 2001; Scambler, 2006), such as how sickle cell identities are negotiated in the context of disabling arrangements and racism (Atkin & Ahmad, 2001). This wider context of inequalities frames the experiences of young people with SCD as they negotiate school relations in the context of chronic illness.

Methods

The data reported here form part of a wider study of the experiences of young people with SCD in schools, including a survey (Dyson et al., 2010) and interviews with young people (May 2007–September 2008). The questionnaire asked about health problems at school, absences, school support and teacher/pupil awareness of and reactions to their SCD. To take one example of how the interview topic guide probed further, the section on reactions to SCD asked respondents to "tell the story of each incident of SCD, including […] reactions of teachers, reactions of pupils […]. Ask about the typicality of each incident […] examples of good support."

Mixed methods research is an approach to research drawing on pragmatism (Teddlie & Tashakkori, 2008), of what works in solving practical research problems (understanding and improving the experiences of young people with sickle cell at school). Cresswell and Tashakkori (2007: 108) suggest that mixed methods approaches contain two distinct questions relating to the respective strands of the research. For this paper the emergent research questions were (in analyzing the survey data) to examine the pattern of disclosure in relation to reported school experiences and (for the interviews) to interpret possible reasons for and against disclosure. As they suggest, we make inferences from each set of data, and report on validation through a triangulation of survey and interview data, though, as Bryman (2007: 21) suggests, reflexive analysis on contextual field notes helps us to forge a "negotiated account of the findings" that makes sense of both the quantitative and qualitative data.

The research was reviewed by De Montfort University and a National Research Ethics Service Multi Centre Research Ethics Committee (07/MRE06/12). Informed consent consisted of age-appropriate participant information sheets and written consent (16 and over) or written assent and carer consent (under 16s). The questionnaire was administered through twelve sickle cell support groups ($n = 113$); sickle cell nurses ($n = 56$) and three outpatient clinics ($n = 400$). Variability in level of understanding by age was addressed, not by adjusting concepts asked about to suit ages, but by permitting, in a quasi-naturalistic manner, each young person and their carer to decide whether the questionnaire was completed by the young person alone (137), by parents only (82), together (271), or with a health professional, voluntary group or researcher (73, and 3 missing data). Characteristics of the sample are given in Table 1.

Forty qualitative taped interviews, using a topic guide, and enabling formulation of questions to be adjusted for age of respondent, were conducted by one of three authors. Again, the young person chose who else was present: mothers (5), fathers (1) and specialist counsellor (1). The interviews took place at hospital outpatients (21); community centre (9); home (3); counselling centre (3), or university (2). The interviews were transcribed in full by the main interviewer (HE) or one of two transcribers. In order to provide additional context for interpretation of data, field notes were kept by the three authors collecting data in association with the interviews or other fieldwork meetings (e.g. meetings to negotiate access). Notes were written up the subsequent day.

Table 1
Characteristics of the sample of young people with SCD.

	Questionnaires		Interviews	
	Number	Valid%	Number	Valid%
Gender				
Female	288	50.6	21	52.5
Male	281	49.4	19	47.5
Total	569	100.0	40	100.0
Age				
4	16	2.8	0	0
5–10	243	42.9	2	5.0
11–18	276	48.7	30	75.0
19–25	32	5.6	8	20.0
Missing values	2	–	–	–
Total	569	100.0	40	100.0
Ethnicity				
Black African	343	60.3	24	60.0
Black Caribbean	162	28.5	15	37.5
Black other	46	8.1	0	0
Other (including not stated)	18	3.2	1	2.5
Total	569	100.0	40	100.00
Completed questionnaire			30	75.0

During analysis these field notes were placed next to the transcript of the interview to which they referred.

The transcripts were read by five of the research team and a thematic approach to analysis applied. This entailed re-reading transcripts, making extensive hand-written notes of possible themes, including copying out quotations in long hand to help fix data in our minds, writing out possible theme titles, annotated with interview and page numbers, and aggregating or disaggregating ideas throughout the transcripts until a list of main themes was constructed. Themes deemed recurrent were independently suggested. The team held two meetings at which the proposed themes were discussed. There was little disagreement among twenty main themes identified (Table 2), differences relating only to how these themes might be aggregated into broader constructs (Armstrong, Gosling, Weineman, & Marteau, 1997).

The frequency of themes across all interviews was then mapped. When writing up qualitative research, there are no rules to suggest how many themes can best represent the diversity of a dataset (Riessman, 2008). Indeed, only one of the themes resulting from our form of thematic analysis is represented here. This theme was partly inductively arrived at and partly derived from our emergent research question: to interpret possible reasons for and against others knowing they had SCD. This theme, dilemmas of disclosing SCD to others, was a theme present in all but one transcript. This theme was interrogated in relation to each individual account, as a means of understanding a particular case; compared across cases by highlighting potential similarities and differences; and related to circumstances of the respondent that could be reasonably justified as an explanation which mediated experience. Finally, the disclosure theme was discussed in the context of the theoretical debates, in addition to the quantitative data.

Our strategy for research contains key features of mixed methods (Tashakkori & Teddlie, 2003). First, as outlined, we use both quantitative and qualitative data. Second, although the timescales of the survey questionnaires and the interviews overlapped, the methods were sequenced in that the questionnaire results were used to inform the sampling for the interviews by seeking diversity of experience in participants invited to be interviewed (see Glaser & Strauss, 1967). Third, we can specify the relationship between the modes of data collection. Having interviewed the first fifteen interviewees opportunistically, we then selected the next ten based on selecting five who had left school aged 16 and five who had continued to post-compulsory education. We further took responses to a specific questionnaire item on the degree to which young people felt they had been enabled to "catch up" school absences associated with their SCD. In doing this we selected ten respondents (five female, five male) who had placed themselves at 0%, 25%, 50%, 75% and 100% in terms of the degree to which they were helped to "catch up" school work missed. We thus generated an interview sample that reflected good, bad and intermediate school experiences. Finally, our approach to enquiry is pragmatic in that it does not assume that the mere fact of combining methods will reveal the "truth". Rather it recognizes that asking questions, whether these produce statistics or qualitative data, is equally an imposition of the researcher onto the social world (Pawson & Tilley, 1997), and that we are as much interested in transforming practice (how young people with SCD experience school) as we are in transforming knowledge through the creation of data. We recognize that we are not only located within what Denscombe (2008) has called communities of practice (policy-orientated social science researchers), but are also embedded, to varying degrees, in sickle cell communities of interest.

Construction of indices

The data from the questionnaires were entered into SPSS by one team member, and a series of six meetings were held between two of the research team to explore the data, and make decisions about what data indices to construct and what statistical tests to apply to the dataset. We were faced with a particular methodological issue. A number of respondents had ticked to indicate that they had not told any school peers about their sickle cell, but within the same question then proceeded to tick to indicate that a particular range of school peers had been told, thus ostensibly contradicting their earlier answer, an inconsistency not evident during piloting. In such cases ($n = 117$) we interpreted the responses as indicating that they *had* told the people indicated, on the grounds that an answer to a specific question was more likely to be accurate compared to an answer to a general question inviting respondents to tick a box if no other children knew.

We also addressed the Bonferroni question (Schaffer, 1995). By virtue of the myriad possible associations between variables one is able to investigate, a number will purportedly indicate significance at the 5% level based purely on the number of tests conducted. For

Table 2
Themes from the Interviews (n = number of respondents).

Attitude to disclosing SCD to others (39)	Mother as advocate in negotiations with school (25)	Denied water during class (19)	Challenges of re-entry to school following absence (13)
School absences (39)	Concern over lack of help to catch up lessons missed (24)	Made to take unsuitable exercise (18)	School physical infrastructure (13)
In pain at school (36)	Denied toilet breaks (21)	Information does not work (17)	SCD as negative capital (9)
Concern about fitting in at school (30)	Called lazy (21)	Being Bullied (16)	Support offered not matching need (8)
Discreditable (28)	Affected by school temperature (21)	Accounting for self (16)	School attempts an innovative response (8)

this reason we aggregated a number of variables into summary counts of the experiences in order to reduce the number of statistical tests applied to the same datasets. We had asked whether the respondent perceived that, respectively, the head teacher, the head of year, most classroom teachers, the PE teacher and the school nurse knew they had SCD. The responses were developed into a count of between 0 and 5 types of adult ostensibly knowing they had sickle cell. Similarly a series of questions about whether other pupils knew they had SCD. Possible answers of no children, a best friend, a number of close friends, most of the school class, or most of the rest of the young people in the school were turned into a count of between 0 and 4, reflecting how wide was the ambit of other pupils who reportedly knew. Next, a series of challenging key events relating to school response to SCD needs were aggregated into a count of 0–4 items, including: being prevented from using the toilet; being denied access to water in class; being made to take unsuitable exercise and being called lazy when tired from the anaemia associated with SCD. Finally, a set of four key indicators of likely clinical severity – having emergency or regular blood transfusions, being admitted to hospital more than three times a year, or taking the drug hydroxyurea – comprised a count of 0–4 with 4 representing the most severe clinical cases.

The young people with sickle cell disorder

Table 1 confirms that here were an equal proportion of females and males in the sample, sickle cell being an autosomal recessive condition and not a sex-linked one. Although, on the advice of our advisory group, our recruitment ranged from 4 years to 25 years old, the majority of respondents were of an age for compulsory schooling in England (5–16).

Most respondents were of Black African/Caribbean descent. Whilst SCD affects all ethnic groups, the greatest numbers currently affected in England are from Black communities. Young people with SCD will therefore not only have to "do" being someone living with chronic illness at school, and "do" gender (Williams, 2000), they will also be "doing" ethnicity (Atkin & Ahmad, 2000). Moreover, negotiations around passing occur in more general contexts, not simply of illness, but of wider inequality including the double consciousness of experiencing racism (Dubois, 2007 [1903]) and sexual identity (Gagné et al., 1997). This means that students who suffer racist discrimination do so in contexts where resisting stereotypes becomes difficult because of physical symptoms: tiredness from anaemia reinforces the racist stereotype of black students as lazy. A social-model-of-disability type resistance to disabling attitudes involves framing a disabled identity in a positive manner. Atkin and Ahmad (2001) suggest that an important strategy for living with SCD is not to frame SCD as central to their identity in the first place. Thus young people with SCD cannot readily employ wider disability strategies to challenge adverse reactions and may thus find themselves further marginalized.

Table 3
Reported severity of SCD (emergency blood transfusion, regular blood transfusions, hydroxyurea drug, 3 + hospital admissions per year).

Number of indicators of severity[a]	Number	%	Cumulative%
0	167	29.3	29.3
1	196	34.4	63.8
2	149	26.2	90.0
3	41	7.2	97.2
4	16	2.8	100.0
	569	100.0	

[a] Numbers refer to how many of the four severity indicators were reported.

The severity of the SCD reported by the sample is given in Table 3. Overall about one-third of respondents reported no indicators of severe clinical symptoms of SCD, with the remainder reporting between 1 and 4 such indicators.

Table 4 (column totals) suggests that over three quarter of the young people in the sample report experiencing at least one the types of negative experiences at school (prevented from using the toilet, prevented from drinking water, made to do unsuitable exercise or called lazy when tired), and over half claim to have experienced two or more of such incident types.

There were no significant differences between males and females in any of degree of reported exposure to negative experiences ($p = 0.123$, df = 5); nor in degree to which they reported telling adults of their SCD ($p = 0.913$, df = 5) nor in disclosing their SCD to other school peers ($p = 0.827$, df = 4); nor in self-reported severity of their SCD ($p = 0.169$, df = 4). In the analysis that follows, responses are not broken down further by gender, nor indeed by ethnicity or age. White and Asian groups were too small to make comparisons with Black groups meaningful. Reported poor experiences increased with age but this is arguably simply a function of years spent exposed to the school environment.

Disclosure to adults

Table 4 (row totals) shows that just over ten per cent of the sample of young people indicated that they thought no adults who might be considered significant in the school context knew that the young person had sickle cell. The range of responses also suggests that the extent to which a range of school staff are felt to know varies considerably from person to person.

Examining individual variables produces a myriad of associations that are not statistically significant, some that are significant at the 5% level, but not at the 1% level (arguably the minimum threshold that should be required, given the number of associations it is possible to look at), and yet others where the presumed direction (the more teachers know, the better they will treat the young person) is actually reversed (see Table 5). For example, PE teachers were even more likely to be reported to compel young people to do unsuitable exercise when it was also reported that they knew the young person had sickle cell.

However, rather than dwell on which of numerous possible associations are/are not statistically significant, we feel there is a more straightforward point to be made. In situations where one or more adults is reported to know the young person has SCD, large

Table 4
Reported range of adults who know young person has SCD compared to reported number of four types of negative experiences associated with school reactions to a young person with SCD.

	Reported number of four types of negative experiences						
Number of the 5 types		0	1	2	3	4	Total
of adults Reported to	0	24	19	5	5	6	59
Know the Person had	1	12	19	13	18	8	70
SCD	2	22	19	13	18	8	70
	3	20	27	42	28	9	126
	4	22	15	23	22	9	91
	5	34	23	17	19	17	110
	Total	134	117	143	119	56	569

Row totals refer to numbers of respondents stating how many of the 5 types of adults (head teacher; head of year; class teacher(s); PE teacher; school nurse) knew the young person had SCD.
Column totals refer to numbers of respondents stating how many of the 4 negative experiences (being denied water; being denied toilet breaks; being made to take unsuitable exercise; being called lazy when tired) they experienced.

Table 5
Associations between numbers of key adults reportedly knowing the pupil has SCD and apparent negative experiences of that pupil.

	Does knowing make a positive, negative or no difference to young person's experiences?	Fisher's Exact Test[d] 2-sided
Head teacher v toilet	No difference	$p = 0.089$
Head teacher v drink	No difference	$p = 0.375$
Head teacher v lazy	Difference[a]	$p = 0.007$
Head of year v toilet	No difference	$p = 0.200$
Head of year v drink	No difference	$p = 0.062$
Head of year v lazy	No difference	$p = 0.245$
Class teacher v toilet	Difference[b]	$p = 0.012$
Class teacher v drink	No difference	$p = 0.305$
Class teacher v lazy	No difference	$p = 0.472$
PE teacher v unsuitable exercise	Difference[c]	$p = 0.002$
School nurse v toilet	Difference[a]	$p = 0.008$
School nurse v drink	No difference	$p = 0.355$
School nurse v lazy	Difference[b]	$p = 0.041$
School nurse v unsuitable exercise	Difference[c]	$p = 0.009$

[a] Strong effect in the direction of better reported care with disclosure.
[b] Effect in the direction of worse reported care with disclosure.
[c] Strong effect in the direction of worse reported care with disclosure.
[d] (Fisher, 1922).

numbers and large proportions of young people report that they have been exposed to one or more negative experiences.

To examine this issue more closely, we developed counts for both numbers of adults reputedly knowing and numbers of negative experiences reportedly undergone. Table 4 represents cross-classification between these two sets of counts, and, as we can see, the responses are spread across both continua. The pattern for Table 4 was investigated further. In particular the cases in the four extreme corners of the table were checked against severity of reported symptoms of SCD.

Table 6 suggests that there are a group of young people with SCD (Row A of the table) where the person has no reported severity indicators, where they are able not to disclose, and where they report no adverse consequences, possibly because they have not suffered symptoms that would either enforce disclosure and/or prompt unsatisfactory responses from school staff. The table further suggests that there are young people (Row B), both with and without severity indicators, who report all bad experiences but where the staff apparently have not been told the young person has SCD.

There appear to be young people (Row C) where the widest circle of school staff are reported to know about the young person's SCD but where there are no reported bad experiences, both for young people with none and some severity indicators. In other words there are 19 young people here who report severe SCD, report letting a wide circle of adults know, and who appear to benefit from this by reporting no bad experiences. Finally, there are respondents with SCD (Row D) who have severe SCD, where the widest ambit of adults reputedly know they have SCD, but where they report having had all the bad experiences. Overall, severity of clinical expression of SCD does not explain the nature of the outcome of disclosure to significant adults at school. It is to the evidence of the taped interviews that we now turn in order to shed further light on this issue.

As discussed, one of the main themes arising from the forty taped interviews was the cost/benefit of disclosing SCD to significant adults at school. The majority of young people with SCD favoured disclosure to teachers, although they this was usually mediated through the mother telling the school at an age when the young person themselves could not readily have communicated this idea. For example one young person said:

> "Yes of course it is important for them to know. Because when I am in pain crisis staff know what to do and they can help me. Also when I am absent they know why and they don't blame me for not being there" [Interview #28, Male, Black Caribbean, 18 years old]

The range of reasons given included the expectation that if teachers knew they would permit or encourage drinking of water in class to prevent dehydration; would understand and permit toilet breaks; would not mistake tiredness for laziness; and would make appropriate allowance for wearing outdoor clothes in class and for moderating participation in PE lessons.

However, three respondents felt that informing teachers carried significant drawbacks. The interviewer checks that the young person is talking about teachers who do know she has SCD, but the young person still reports:

> "Right. Teachers, some of them are understanding because [they think] that I would do the work if I could. But they understand that I do get tired. Erm, some teachers will think I am lazy. And I'm thinking, if you give me the work, I'll take it home and do it when I can, when I [get] a burst of energy. But some teachers think I'm lazy [..] so they're like 'How do you/are you cheating, duh duh', and like I do know the material." [Interview#1, Female, Black Caribbean, 16 years old]

Other perceived disadvantages to disclosing to teachers included teacher reactions of sarcasm (for wearing a coat indoors); being called a "drama queen" (for complaining about being in pain), and being invited by the teacher to "wet yourself" when needing the toilet. The fear of provoking such negative reactions, on top of having to deal with SCD symptoms, leads two other respondents to express ambivalence about disclosure to teachers. The ambivalence may derive from anticipation of negative reactions rather than actual experience, or possibly from the manner in which caring attitudes draws unwanted attention to the young person:

> "It's like they make sure I am all right. [That] I am well, if I need a drink of water. It's like I would say no, no I am all right. I felt like they wanted to do something and they take it out of proportion. I am really/don't want that…… you know it is hard to say no" [Interview#38, Male, Black African, 17 years old]

Table 6
A comparison of extremes of reported exposure to negative experiences[a] and reported disclosure to adults[b] by young people with SCD with the relative reported clinical severity of their SCD.[c]

	Relative severity of SCD		Total
	Not severe (0)	Severe (1–4)	
A. No adults know, No bad experiences (Cell 0,0 from Table 4)	19	5	24
B. No adults know, all bad experiences (Cell 0, 4 from Table 4)	3	3	6
C. All adults know, no bad experiences (Cell 5,0 from Table 4)	15	19	34
D. All adults know, all bad experiences (Cell 5,4 from Table 4)	1	16	17

[a] Negative Experiences: being denied water; being denied toilet breaks; being made to take unsuitable exercise; being called lazy when tired.
[b] Reported Disclosure to Adults: how many of the 5 types of adults (head teacher; head of year; class teacher(s); PE teacher; school nurse) knew the young person had SCD.
[c] Relative Reported Clinical Severity of their SCD: number of indicators of clinical severity of SCD (emergency blood transfusion, regular blood transfusions, taking the drug hydroxyurea, 3+ hospital admissions per year).

A downside to the caring attitude of teachers is that it focuses unwanted attention on to the young person with SCD, who finds it hard, given that some teachers would not permit drinks and toilet breaks, to reconcile the fact that his teachers are doing so, are expressing caring attitudes by checking, but in a manner which he finds both discomforting and difficult to resist. This does suggest the high degree of skill implicitly desired of the teachers: to be knowledgeable, concerned and attentive about a condition with myriad and variable complications, but in a discrete and unobtrusive manner.

Disclosure to peers

In this section we consider how the young people recount their relationship with their peers in terms of disclosing their SCD. Table 7 [row totals] indicates that just under ten per cent of the young respondents thought no school peers knew about their sickle cell. Once more, the data suggest young people with SCD situate themselves fairly evenly at all points of the continuum between telling no-one and most other pupils in the school knowing about their sickle cell. The 117 respondents who ticked ostensibly contradictory are discussed below under data validation.

Table 7 represents a cross-classification between the number of reported negative experiences and the range of school peers who reportedly are aware that the young person has SCD. As in Table 4 for adults, replies are varied across both dimensions of the table. The configuration of responses for Table 7 was once more investigated through an examination of the four extremities of the table.

As was the case with ostensible disclosure to adults (see Table 6 above), Table 8 suggests that there is no necessary connection between severity of symptoms, disclosure and reported negative experiences at the hands of the peers of the young person with SCD. A wide range of school peers reputedly knowing their associate's SCD status may equally be associated with good (Row C) or poor (Row D) experiences. One possible interpretation of Row E is that the apparent ambivalence about whether or not to declare SCD to school peers may be because these respondents have yet to experience a critical incident that would stand as a test of the wisdom of disclosure. This greater uncertainty was also reflected in the interviews.

In the interviews, the pattern of replies concerning the pros and cons of disclosure to school peers was considerably different. Approximately equal numbers were, respectively, in favour of disclosure; against disclosure; were balancing reasons for and against; or were ambivalent about disclosure.

Table 7
Reported range of school peers who know young person has SCD compared to reported number of four types of negative experiences associated with school reactions to a young person with SCD.

		Reported number of four types of negative experiences					
Number of the 4 types of peers reported to know the person had SCD		0	1	2	3	4	Total
	0	17	9	15	8	3	52
	1	5	13	27	15	4	64
	2	29	27	30	29	19	134
	3	19	24	25	25	7	100
	4	13	18	27	25	19	102
	Contradictory	51	26	19	17	4	117
	Total	134	117	143	119	56	569

Row totals refer to numbers of respondents stating how many of the 4 types of peers (best friend; group of friends; whole class; whole school) were reported to know the person had SCD.
Column totals refer to numbers of respondents stating how many of the 4 negative experiences (being denied water; being denied toilet breaks; being made to take unsuitable exercise; being called lazy when tired) they experienced.

Table 8
A comparison of extremes of reported negative experiences[a] and reported disclosure to school peers[b] by young people with SCD with the relative reported clinical severity of their SCD[c].

	Relative severity of SCD		Total
	Not severe (0)	Severe (1–4)	
A. No children know, No bad experiences (Cell 0,0 from Table 7)	12	5	17
B. No children know, all bad experiences (Cell 0, 4 from Table 7)	0	3	3
C. All children know, no bad experiences (Cell 5,0 from Table 7)	3	10	13
D. All children know, all bad experiences (Cell 5,4 from Table 7)	3	16	19
E. Contradictory, No bad experiences (Cell 'Contradictory',0 from Table 7)	32	19	51
F. Contradictory, All bad experiences (Cell 'Contradictory', 4 from Table 7)	1	3	4

[a] Negative Experiences: being denied water; being denied toilet breaks; being made to take unsuitable exercise; being called lazy when tired.
[b] Reported Disclosure to School Peers: how many of the 4 types of school peers (best friend; group of friends; whole class; whole school) knew the young person had SCD.
[c] Relative Reported Clinical Severity of their SCD: number of indicators of clinical severity of SCD (emergency blood transfusion, regular blood transfusions, taking the drug hydroxyurea, 3+ hospital admissions per year).

For seven respondents disclosure to peers was a positive. Even in the face of possible teasing that was not "negative in a bad way, it was more negative in an ignorant way", disclosure became a major strategy in negotiating life at school with SCD:

> "I don't think there's any disadvantage of telling people. I think that there's a disadvantage in not telling people because if you don't tell them they're not sure of what the facts are and if someone doesn't know, well you might get scared of it. It's like the whole thing of you have a monster in the cupboard when you're a kid, if you don't open the cupboard and look if there is a monster, then there is a monster. So if you let people know that you are sickle cell anaemic, it's nothing to worry about. It's a condition. It's not a disease, you can't catch it. Let them know, what happens, how you get it, and explain it, then they know for themselves" [Interview# 39, Male, Black Caribbean, 17 years old]

Other reasons advanced in favour of disclosure by other respondents included: remaining in contact when ill, visiting when in hospital; gathering together and bringing school work to their home to help them catch up; seeing their point of view when they were in pain; reminding the teacher about the fact their friend has an illness or specifically about drinks or toilet breaks; lending coats to keep warm; preventing teasing; keeping the person company as they walk slowly between lessons, and helping in practical ways like carrying school bags.

Whereas a majority were in favour of teachers knowing, in the case of pupils the young people with SCD were divided in their opinion, and four expressed clear views against disclosure. This related predominantly to perceived potential or actual bullying and teasing. One male respondent recounted:

> "[Their reaction] was frightening. Some start to make up stories and things like that, and they started spreading rumours which was not true […] they started saying stupid things like I am not well and things like that…… things like a person with sickle cell will die if they get hurt or something like that. You have to be very careful in dealing with them. Something disgusting like that. It was deeper than that…. it was hurtful." [Interview#35, Male, Black African, 17 years].

The young man reports that he had only reluctantly told his school colleagues "because last year I just had to find out that they

know I have the illness, so I thought I'd better tell them". This implies a decision to disclose under duress, because, in Goffman's terms, it was felt to be better to discredit oneself than to have others do it for him. Other reasons why disclosure was felt to be a disadvantage included reported experiences that those told would spread the information to others indiscriminately; that others did not talk to them or sit next to them in class; that they would be the subject of taunting (about yellow eyes, about having a transmissible disease; about being physically inept); that it would be the site around which fights were provoked; and that the other youngsters would not understand what sickle cell entails.

One of the five respondents who balanced reasons for and against disclosure to school peers recalls being helped by his classmates at school:

> "The ones who really cared for me they really looked out for me. And if I like I had trouble, they go downstairs or upstairs in the school, because we have lots of stairs in the school they would carry my bag. Or if the bus is driving past and I was going home from school, they put me on their shoulder and carry me to the bus, and they carry me into the bus, so they had been good." [Interview# 9, Male, Black Caribbean, 25 years old].

He reports appreciating the help he received when tired with his anaemia and when his mobility was impaired. However, he also recounts reasons against disclosure.

> "I used to get teased really, because the way I walked, they see me walking with pain […] Yeah, I have been teased for having sickle cell at school, erm, I [was] bullied a few times because I was sick, yeah, that was really painful […] basically they will take the mick [short for 'take the mickey' = tease] out of like sickle cell and try to say something because I was so ill, and ask me silly questions about it. And although I told them a few times what it is, what it does do, from my knowledge at that age, yeah they still come back [and tease me about it]" [Interview# 9, Male, Black Caribbean, 25 years old]

Eight respondents were uncertain about disclosing their SCD to peers. A major reason for this ambivalence was the apparent tension between acknowledging the reality of the sickle cell, whilst not wishing it to become a central feature framing all one's life's experiences.

> "I mean I've had a couple of friends come and stay with me for a drug infusion. That was kind of weird, but it was good at the same time, because you don't really want people there but it wasn't, it wasn't as bad as I thought it would be, so it was quite good. But erm, yeah, it's good that I don't tell them every little thing about it […] I tend not to think of it as an excuse for anything, so I don't really, I just don't, I don't feel for everyone to know that I'm having a problem with this or a problem with that or I might have an operation or anything like that. I just, I just/ and also the pity and "Oh my God" duh, duh, duh. It's like fine, I've lived with it forever, it not different to anything I know. There's no reason for you [her peers] to be too clingy and sorry for me, that's a bit 'no no' " [Interview# 15, Female, Black African, 13 years old]

Other ambivalence in the interviews included the anticipation that there would be different reactions from different sections of the peer group: some enquire further in a positive way about SCD, whilst others would "turn their backs." In another instance the the same peer would react differently at different times. A 15-year old Black Caribbean girl felt that others knowing her condition could sometimes mean exclusion from their games, but at other times inclusion in their games on the basis of some adjustments.

In summary, our respondents were for or against the principle of disclosing their SCD to school peers, a preference expressed with varying degrees of intensity. Others were ambivalent about disclosure, vacillating between the two positions of disclosing and concealing. Still others held a balancing view, giving credence both to disclosure and non-disclosure. The majority were selective in their attitude, drawing a distinction between adults in authority where most felt it was important for them to know, and peers, where the opinions on the relative merits and demerits of disclosure were far more varied.

Data validation and limitations to the study

We offer one element of reflexive analysis, derived from our field notes, which both possibly explains contradictions within the data, and serves as an indicator of the credibility of our interpretations of the data. We were concerned with making sense of these contradictions within a more reflexive engagement, which while accepting the concept of validity raises important questions, does not regard it as the only criteria on which to judge research. There is more of a concern with credibility, which reflects 'truth' is contingent. In collecting questionnaire data, one of the team attended a support group meeting. Fifteen parents and nineteen young people with SCD were present. Having explained the questionnaire, young people and/or their parents began to complete the task. The researcher sat alongside one fourteen-year old boy as he completed the questionnaire. His mother sat opposite, helping his younger brother complete a questionnaire. For each of four questions asking about key experiences at school (see Table 4) the young man answered "no" as the researcher read the questions aloud. Each time the mother overheard his answer and invited him to remember a specific occasion he had experienced the negative event. On each occasion he agreed that he had indeed experienced the negative event. However, he did so with a resignation that seemed to indicate that he was desperate for his life at school to be as normal as possible, so much so that he was apparently prepared to pass over his negative experiences. It is plausible that, for some of the 117 who gave ostensibly contradictory answers (see Table 7), their initial answer to the question (no other child knows I have SCD) reflected a desire not to disclose their SCD. However, when subsequently confronted with a more specific question about a particular person knowing that they had SCD, they reluctantly acknowledged that particular people were aware they had sickle cell, even though they wished that no-one else knew.

We do not think the initial reply of the young person was 'wrong': it reflected his reality that being normal consisted of *not* being subject to certain experiences. For us, the young boy acknowledged the veracity of what his mother said but was unhappy at the position this placed him in because he was thereby not 'normal'. This makes sense of the quantitative and qualitative data. The alternative account (that mothers over-dramatize experiences of their off-spring for purposes of securing attention/ resources) is not borne out by the interviews where 33 of 40 interviewees were alone and recounted negative events at similar rates to the survey (Table 9).

Moreover, there was no significant association (Fisher's exact test, 2-sided) between completion for the questionnaire with and without parents present for three key variables: being denied toilet breaks ($p = 0.362$, $df = 1$); being denied water in class ($p = 0.479$, $df = 1$); or being made to take unsuitable exercise ($p = 0.166$, $df = 1$). A significant association between being called lazy and presence/absence of parents in completion of questionnaire ($p < 0.001$, $df = 1$) was in the direction of young people being more likely to assert this when alone, and in the opposite direction of any concern that presence of a parent leads to over-reporting of events.

This research has represented a first, limited, attempt to describe the school experiences of young people with SCD in

Table 9
Comparison of reporting of negative events, questionnaires and interviews.

	Questionnaire $n = 569$	Questionnaire %	Interview $n = 40$	Interview %
Denied water	260	45.8%	19	47.5%
Denied toilet breaks	326	57.4%	21	52.5%
Made to take unsuitable exercise	206	36.3%	18	45%
Called lazy when tired	192	33.8%	21	52.5%

England. The data are *reported* data, and clinical severity is based on self-report not medical records. The voices of teachers, perhaps struggling to include pupils with chronic illness in mainstream classes, are currently being investigated with a survey of schools attended by pupils with SCD. The perspectives of students without SCD have not been sought within this research programme. However, we must be careful not to mourn the lack of voice given to teachers and able-bodied pupils: as Becker (1967) argues, theirs are the dominant discourses and revealing the subordinate voice is always discomforting in the "hierarchy of credibility".

Conclusion

This paper has used a mixed methods approach in an attempt to describe and understand the experiences of young people with SCD at school, examining the relationship between significant others being aware of their SCD status and their reported experience of enabling or disabling responses. In the survey, there was no discernible overall association between reports that either responsible adults or peers at the school knew that the young person had sickle cell and the level of negative experiences at school reported by the young person or parent. There were, though, large numbers and large proportions of young people reporting negative experiences in conjunction with disclosure to teachers and/or peers. The question of the consequences if a young person with SCD discloses their sickle cell status, and to whom they disclose, is incredibly sensitive to context. The interviews permit us some insights into the nature of these contexts.

It is clear that many of the young people with SCD are aware that there are potential costs and benefits to disclosure. But some of the responses at interview suggest uncertainty about whether significant adults or peers "know" they have SCD. This leads us to consider what is meant by "knowing" a young person has SCD. In the questionnaires about 10% of replies suggest that neither adults nor peers have been told, but the variable and discreditable aspects of SCD do not necessarily mean that teachers and pupils may not know the young person has SCD. Equally, the young person and/or parent could claim to have told the school verbally or in writing. But the term "sickle cell disorder" written on a school health form may convey nothing about the symptoms, and the preventive and precautionary measures required to fully support a young person with SCD at school. Furthermore, informing the school in the form of a key figure such as head teacher or head of year does not guarantee that this information will be passed on to classroom teachers, nor to newly appointed teachers, nor to supply teachers, nor between school years, nor at the point of school transfers. A number of our respondents intimated that teachers knew but did not understand, that is they knew the label SCD but did not appreciate the range of health protection responses that this required of them. Sometimes teachers in busy settings forgot that the young person has SCD, and on occasions the teacher apparently ignored, punished or mocked the young person with SCD. The information about SCD degrades in various ways and at various points of the system, and mothers in particular described battling with the school to persuade the authorities to take the young person's SCD seriously. On three occasions the intervention of an outsider with professional authority, such as a specialist sickle cell worker, appeared to make a difference. The issue is not just what "knowing" a young person has SCD means, it is also a question of *how* adults or peers become cognisant of the young person with SCD. An illness episode or school absences may require the young person to account for themselves to adults and/or to peers and previous successful passing may be replaced with a reluctant disclosure under duress. The emotional and practical consequences of revelation under duress also merit further study. Given that more generally school climate has been found to effect well-being (Kuperminc, Leadbeater, & Blatt, 2001), and that some who disclosed did feel well supported, further research could be conducted on the effect of the ethos of schools on students with sickle cell.

SCD has yet to become part of the mainstream cultural repertoire of society (Anionwu & Atkin, 2001) or of school settings. Consequently, the term sickle cell disorder does not yet signify an extremely painful multi-system, variable, chronic illness. A national survey of young people with SCD suggests that disclosure to significant adults in the school system and to their school peers does not necessarily improve their experience. Interviews with the young people with SCD suggest that they themselves are acutely aware that disclosure is a double-edged sword. In the main their perceptions are that 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 disclosure amounted to the hope that the information would be acted upon to empathise (as long as this did not amount to sentimentality); make reasonable adjustments to facilitate preventive measures, advocate on their behalf, help in practical ways when this was needed, and 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. Whatever emotional cost may be entailed by passing, it remains important to recognize that a key strategy for living with SCD is that sickle cell is not framed as central to their identity in the first place. The rationalist expectation, that informing others will reduce stigma, does not hold good in this study. This suggests the need for strong supportive school frameworks, without which young people with SCD may not benefit from preventive and precautionary measures to protect health. Changing the wider social and physical environment of the school is necessary so that young people with SCD are supported irrespective of whether or not they themselves choose to foreground or downplay their sickle cell identity.

Acknowledgments

This paper was funded by the Economic and Social Research Council (Grant RES-000-23-1486). We are grateful to all the young people and their families for their time in replying to the survey. We would like to acknowledge the work of the Sickle Cell and Education group (SCED) in helping with the survey, including David Rees, Moira Dick, Susan Height, Sandra O'Driscoll, Shirley Samuel, Baba Inusa, Jo Howard, Helen Appleby, Neil Westerdale, Lola Oni, Elizabeth Okuyiga, Vesna Graham, Beatrice Barbola, Gavin Cho, Michele Afif, Lurieteen Miller, Susan Crawford, Maureen Williams, Janet Lawrence, Paulette Gaskin, Wendy Mills, Sekai Tangay, Bernice Burton, Comfort Okolo, Evelyn Chibambo, Beverley Smalling, Anthony Akhidenor, Mary Opare-Ababio, Joanne McLoughlin, lyamide Thomas, Comfort Ndive, Blanche McCalla, Anthony Mason, Carol Nwosu, Cecilia Shoetan, Tito Idowu, Eileen Bowen, Susan Mew, Beverley Bell-Jessop, Maureen Scarlet, Monica Noel, Carol King, Winston Nurse, Melita Dixon, Angela Dias, Sonia Lindsay, Sharon Wilson, Anndeloris Chacon, and Marjorie Ritchie.

Supplementary data

Supplementary data associated with this article can be found in the online version, at doi:10.1016/j.socscimed.2010.03.010.

References

Anionwu, E. N., & Atkin, K. (2001). *The politics of sickle cell and thalassaemia*. Buckingham: Open University Press.

Armstrong, D., Gosling, A., Weineman, J., & Marteau, T. (1997). Research note: the place of inter-rater reliability in qualitative research: an empirical study. *Sociology, 31*(3), 597–606.

Atkin, K., & Ahmad, W. I. U. (2000). Living with sickle cell disorder: how young people negotiate their care and treatment. In W. I. U. Ahmad (Ed.), *Ethnicity, disability and chronic illness* (pp. 45–66). Buckingham: Open University Press.

Atkin, K., & Ahmad, W. I. U. (2001). Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine, 53*(5), 615–626.

Becker, H. (1967). Whose side are we on? *Social Problems, 14*, 239–247.

Bryman, A. (2007). Barriers to integrating quantitative and qualitative research. *Journal of Mixed Methods Research, 1*(1), 8–22.

Ciutto, L., Conti, E., Evans, H., Lewis, R., Murphy, S., Rautiainen, K. C., et al. (2006). Creating asthma-friendly schools: a public health approach. *Journal of School Health, 76*(6), 255–258.

Cresswell, J., & Tashakkori, A. (2007). Developing publishable mixed methods manuscripts. *Journal of Mixed Methods Research, 1*(2), 107–111.

Cunningham, M. M., & Wodrich, D. L. (2006). The effect of sharing health information on teacher's production of classroom accommodations. *Psychology in the Schools, 43*(5), 553–564.

Denscombe, M. (2008). Communities of practice: a research paradigm for the mixed methods approach. *Journal of Mixed Methods Research, 2*(3), 270–283.

Dubois, W. E. (2007 [1903]). *The souls of black folks*. Oxford: Oxford University Press.

Dyson, S. M., Abuateya, H., Atkin, K., Culley, L. A., Dyson, S. E., & Rowley, D. T. (2010). Reported school experiences of young people living with sickle cell disorder in England. *British Educational Research Journal, 36*(1), 125–142.

Fisher, R. A. (1922). On the interpretation of Chi-Square from contingency tables and the calculation of *P. Journal of the Royal Statistical Society, 85*(1), 87–94.

Gagné, P., Tewksbury, R., & McGaughey, D. (1997). Coming out and crossing over: identity formation and proclamation in a transgender community. *Gender and Society, 11*(4), 478–508.

Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Goffman, E. (1968). *Stigma: Notes on the management of spoiled identity*. Harmondsworth: Penguin.

Hogg, C., & Modell, B. (1998). *Sickle cell and thalassaemia: Achieving health gain*. London: Health Education Authority.

Koontz, K., Short, A. D., Kalinyak, K., & Noll, R. B. (2004). A randomized controlled pilot trial of a school intervention for children with sickle cell anaemia. *Journal of Paediatric Psychology, 29*(1), 7–17.

Kuperminc, G. P., Leadbeater, B. J., & Blatt, S. J. (2001). School social climate and individual differences in vulnerability to psychopathology among middle school students. *Journal of School Psychology, 39*(2), 141–159.

Lightfoot, J., Muhkerjee, S., & Sloper, P. (2001). Supporting pupils with special health needs in mainstream schools: policy and practice. *Children and Society, 15*, 57–69.

Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: young people's views. *Child Care, Health and Development, 25*(4), 267–283.

Lingsom, S. (2008). Invisible impairments: dilemmas of concealment and disclosure. *Scandinavian Journal of Disability Research, 10*(1), 2–16.

Link, P., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363–385.

Lonardi, C. (2007). The passing dilemma in socially invisible diseases: narratives on chronic headache. *Social Science & Medicine, 65*(8), 1619–1629.

Low, J. (1996). Negotiating identities, negotiating environments: an interpretation of the experiences of students with disabilities. *Disability, Handicap and Society, 11*(2), 235–248.

Mukherjee, S., Lightfoot, J., & Sloper, P. (2000). The inclusion of pupils with a chronic health condition in mainstream school: what does it mean for teachers? *Educational Research, 42*(1), 59–72.

NHS Sickle Cell and Thalassaemia Screening Programme. (2006). *Sickle cell disease in childhood*. London: NHS Sickle Cell and Thalassaemia Screening Programme and Sickle Cell Society.

Noll, R. B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W. M., & Davies, W. H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development, 67*, 423–436.

Okpala, I. (Ed.). (2004). *The practical management of haemoglobinopathies*. Oxford: Blackwell.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: MacMillan.

Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. London: Sage.

Renfrew, D. G. (2004). A cartography of passing in everyday life. *Symbolic Interaction, 27*(4), 485–506.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.

Scambler, G. (2006). Sociology, social structure and health-related stigma. *Health, Psychology and Medicine, 11*(3), 288–295.

Schaffer, J. P. (1995). Multiple hypothesis testing. *Annual Review of Psychology, 46*, 561–584.

Tashakkori, A., & Teddlie, C. (Eds.). (2003). *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage.

Teddlie, C., & Tashakkori, A. (2008). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches on the social and behavioural sciences*. Thousand Oaks, CA: Sage.

Williams, C. (2000). Doing health, doing gender: teenagers, diabetes and asthma. *Social Science & Medicine, 50*(3), 387–396.