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# Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder

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## Abstract

This qualitative paper explores the strategies and resources young people use to cope with sickle cell disorder or thalassaemia major, two haemoglobin disorders with serious implications for health and survival. By focusing on coping strategies, we explore how young people attempt to take control over their lives. The respondents, largely of South Asian and African Caribbean origin, aged between 10 and 19 years, valued maintaining a 'normal' life and struggled to achieve this normalcy. Strategies were employed to minimise difference from peers but these strategies remained vulnerable. Coping occurred in a dynamic space, involving negotiation and engagement with both personal and structural factors. Threats to normalcy did not always reside in the condition; life transitions, changes in social relationships and racist, disablist or sexist marginalisation also threatened coping strategies. © 2001 Elsevier Science Ltd. All rights reserved.

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## Introduction

This paper explores how young people live and cope with a sickle cell disorder (SCD) or thalassaemia major, two serious recessive haemoglobin disorders, with life-limiting and potentially debilitating consequences. We address the worries and difficulties young people face, the coping resources and strategies they employ to live a 'normal' life, and the wider social factors which can support or undermine their coping strategies. By focusing on coping strategies we emphasise how young people can take control of their life and underline the importance of not seeing them as tragic victims at the mercy of their illness (see Morris, 1993). At the same time, by locating our discussion within the broader social context, we also suggest that many of the difficulties they faced are a consequence of the wider society's inability to accommodate 'difference' (see Oliver, 1996; Barnes, Mercer, & Shakespeare, 1999).

Such a broad approach is important because much previous work on haemoglobinopathies, largely located within the 'medical model', neglects the social and

political aspects of these conditions. Discussions about the social construction of disability and chronic illness, and the relevance of racism to the experience of impairments have only recently begun to penetrate this literature (see Priestley, 1999; Ahmad, 2000). These debates, in addition to providing invaluable insights, offer a more general reminder that living and coping with a chronic illness occurs within a dynamic space, involving negotiation and engagement with structural and personal factors, as well as historical and present-day social relationships (see Bourdieu, 1977). With this as our starting point, we offer an account of young people's lives in which individual responses to their illness are discussed within a broader social context.<sup>1</sup>

<sup>1</sup>Such an approach necessarily synthesises a wide range of literature, covering a range of theoretical approaches, underpinned by very different assumptions. Much of the psycho-social literature, for instance, offers a narrow empirical focus (see Thompson, 1994), whereas debates about ethnicity and the social construction of disability suggest a more political engagement (see Oliver, 1996; Ahmad, 2000). Nonetheless, these different bodies of literature are important in contextualising our discussion.

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We begin our account, however, by providing a necessary summary of the two conditions. This provides an important background for locating the young people's narratives but raises, as we shall see, a constant — but perhaps necessary — tension between the 'medical' and 'social' models of disability. SCDs and thalassaemia major are recessive blood disorders where individuals who inherit a deleterious gene from both parents develop the disease. In the UK the groups most at risk of SCDs are of African Caribbean or West African origin. The thalassaemia gene is more commonly found among Cypriots, South Asians and Chinese, and less commonly among African Caribbean and white British people. SCDs include sickle cell anaemia, haemoglobin SC disease and sickle beta-thalassaemia. All have similar consequences; they are variable, unpredictable and, at times, life threatening. Those with SCDs are prone to 'sickling' of the red blood cells, causing blockages in smaller blood vessels and resulting in 'the painful crisis', as well as anaemia, leg ulcers, stroke and damage to various parts of the body including the spleen, kidneys, hips, eyes and lungs. Affected children are also vulnerable to conditions such as pneumonia and meningitis. Treatment and care include the prevention of life-threatening infections, pain management and the avoidance of circumstances that cause the red blood cells to 'sickle'. A child born with thalassaemia major is unable to make a sufficient amount of haemoglobin and needs blood transfusions every 4–6 weeks, for life. Excretion of excess iron acquired through transfusions requires injections of a drug such as desferrioxamine (desferal), using a battery-operated infusion pump for 8–12 h a day, 5–7 nights a week. Many of the complications associated with thalassaemia major result from non-compliance with the daily infusion pump. This causes 'iron overload' and can affect various organs. Specific complications include diabetes, delay or failure to enter puberty and heart problems. Death through non-use of the infusion pump is not uncommon. Other problems can include infections, such as hepatitis C, acquired through blood transfusions.

### The study

The aim of the research was to provide a detailed understanding of young people's experience of living with these conditions. We conducted in-depth interviews with 26 young people with SCD and 25 young people with thalassaemia major (age range 10–19 years). Each young person was interviewed twice over a 6-month period. We hoped that this would enable our analysis to reflect on the variability of the condition. This proved only partially successful. We were able to detect some changes in the young person's response, especially if they

had recently experienced a painful crisis or were about to have a blood transfusion. This, unfortunately, was rare (see below). Consequently, the two sets of interviews are treated as a general resource and the dynamic influence of the illness was constructed by the young person themselves as they reflected, often in retrospect, on living and coping with a haemoglobin disorder. Conducting two interviews, however, did enable us to explore this dynamic in greater detail and this proved especially valuable in exploring, for instance, the vulnerability of their coping strategies. By talking to the child twice, we were able to re-introduce issues mentioned in the first interview and clarify their meaning for the child, often in relation to a different set of circumstances.

Young people were offered an interviewer of their own sex and except for three cases (a 13 year old African Caribbean female, a 19 year old Asian female and a 16 year old African Caribbean male) took up our offer. This is perhaps not surprising since the interviews were likely to touch on sensitive issues. Young people were also offered an interviewer of their own ethnic background. This, however, seemed less important to them and only one Asian boy and two Asian girls requested this; this is in contrast to our previous work, focusing on the experience of parents.<sup>2</sup> All interviews were conducted in English and were tape-recorded.

The sample was drawn from the records of health professionals, such as paediatricians and specialist haemoglobinopathy workers, in eight localities in the Midlands and Northern England. In all areas but one, the sample represented all known cases of SCD and thalassaemia. In the one remaining area, respondents were randomly selected to reach the target sample of 25. The eventual sample of those with SCD included 12 males and 14 females. Eighteen of the 26 children had sickle cell anaemia; five had sickle beta thalassaemia; two had SD disease; and one had SE disease. The average age of the sample was 14.2 years and the mode was 12 years. In terms of ethnicity, 19 described themselves as 'African Caribbean'; six 'mixed'; and one as 'Indian Hindu'. In terms of family structure, nine young people lived with both of their 'natural' parents, four with their mother and step-father and one with foster parents. Twelve young people lived with one parent, always their mother and nine of these had regular contact with their father. The mean family size was 4.3 (including the person with SCD). Eighteen of those with SCD were still at school, five were at college and two were seeking work.

For those with thalassaemia, the sample included 12 males and 13 females. Their average age was 13.9 years

<sup>2</sup>The ethnic background of the interviewer, from the parents' point of view, became important, for reasons of both language and cultural sensitivity (see Atkin & Ahmad, 2000a).

and the mode was 11 years. In terms of ethnicity, 22 were Pakistani Muslims; one was Bangladeshi Muslim; one an Iranian Muslim; and one Indian Hindu. Twenty-one young people lived with both 'natural' parents. Two lived with widowed mother and one lived with his divorced mother, but still had regular contact with his father. Another young person lived with his brother and his brother's wife, who were his legal guardians. Three young people lived in three-generational households and the mean family size was 6.8 (including the person with thalassaemia). Fifteen young people were still at school; seven were at college; two were seeking work; and one was at University.

The project used qualitative methods and analysis, based on semi-structured interviews. Such methods allow an examination of complex and contingent situations, behaviours, beliefs and interactions (Mishler, 1986). A topic guide (in two parts for the two interviews) identified a number of key themes we hoped to explore during the interview. This guide was developed from a review of the relevant literature on haemoglobinopathies, chronic illness and ethnicity and welfare; discussions with key informants; advice from an 'expert' advisory committee; and our own previous work, evaluating service support for children with SCD or thalassaemia (see Atkin, Ahmad, & Anionwu, 1998; Atkin & Ahmad, 2000a). The purpose of the interview was to get the child to talk about their illness within the broader social context with which they engaged. Rather than assume that the illness would dominate their narratives, we created a more general topic guide that probed family relationships, life transitions and social networks. Complete interviews were fully transcribed and organised according to analytical headings. Following accepted conventions of qualitative analysis (Gubrium & Sliverman, 1989), we took information from the transcripts and transferred it onto a map or framework, allowing comparison by theme and case. The respondents' accounts were organised by categories and sub-categories, from the topic guides as well as new categories we drew from our analysis of transcripts. The material included under each heading reflected both the range and the frequency of respondents' views on particular issues and formed the basis of generalising their experience. This enabled a comparative analysis of different aspects and variations in experience, as well as the significance of the individuals' background in making sense of this experience. From this we defined concepts, accounted for patterns and ranges, and established linkages and explanations.

In the accounts that follow, pseudonyms are used to protect respondents' identities. The findings are divided into two broad but overlapping sections. The first, focuses on the strategies young people employed in coping with their illness. The second section discusses how young people cope with the responses of others

around them. We locate the findings within relevant literature on young people, chronic illness and ethnicity, as we proceed. This, as we have argued above, is an important aspect of our account.

### **Coping with a chronic illness**

SCDs and thalassaemia major are serious, life-limiting and potentially life-threatening conditions. Coping with serious chronic illness or disability requires resources and strategies (Beresford, Sloper, Baldwin, & Newman, 1996). Thus the ability to cope, is neither entirely located in the individual psyches nor related simply to the severity of the condition (Priestley, 1999). Here we explore the range of strategies and resources, which allowed young people to get on with life. In doing so we explore how an individual engages with their illness within the broader context of life transitions, family life and social relationships.

Not surprisingly, respondents found their illness difficult to cope with but regarded this as a natural response to their condition. Viewing their response as 'normal' allowed them to maintain a positive self-identity. Such a sense of normalcy was also sustained by comparing themselves to children with other chronic illnesses and disabilities, including those who were worse off than themselves; ironically, this casts others as 'victims', a definition they resisted for themselves. Rashid Mustaq (16) remarked:

I'll just say well thank God I've got this, I don't want to be worse off like. What if I was like, no ears and no eyes, I'm really thankful about that. There are a lot worse off than me.

Such comparisons, however, also reflected the value young person placed on 'being like' their peers. This emerges as an important coping strategy, albeit one — as we shall see — that is frequently challenged. Their arguments with parents as well as their concerns and worries were similar to those of their peers (see Brannen, Dodd, Oakley, & Storey, 1994; Jenks, 1996). This included, doing well at school, getting a job and being accepted by their peers. The young people's experience of chronic illness cannot be discussed in isolation of the broader context of 'growing-up' and life transitions. Coping with the emerging expectations and responsibilities of 'growing up' is common among all young people (Dornbusch, Patersen, & Hetherington, 1991) and although having a chronic illness complicates the process, it does not fundamentally alter it (see Hilton, Osborne, Knight, Singhal, & Serjeant, 1997). This theme will re-occur throughout our analysis.

A small minority — largely under 12 — claimed to face little difficulty in living with their illness; the illness

rarely 'got them down'. This was not a form of denial: these respondents understood the potential consequences of their illness and the problems of treatment. It was more that they had not overtly begun to question their difference. Parental support offered them considerable protection both from the practical problems of the condition and the negative views and actions of others. This protection, however, becomes more difficult as they grow older and begin to become aware of their personal and social difference and disabling responses of others, while also accommodating the consequences of their conditions as they develop more complex and broader social relationships. Most older respondents, therefore, admitted there were times when they asked 'why me?'. Such questions usually began to occur at about the age of 12 years in relation to comparisons with peers and the limitations imposed by their illness. Aysha Habib exemplifies the resultant ambivalence:

Sometimes I will be happy, sometimes I will be crying and stuff like that. To tell you the truth I don't know why I get mad. I just don't know, why have I got thalassaemia?

As we will see, for most respondents, coping strategies remain vulnerable to both changes in the condition, in personal and social circumstances and the disabling attitudes of others.

Questions about 'why me?' never entirely go away and often re-occur during stressful events, crisis associated with the condition, changes in status and life transitions. Such events often heightened their sense of difference to peers, undermined their notions of normalcy and made coping difficult:

Because when I looked around and when I looked at my cousins, they were fine, they had no problems with life, that I know of, they were fine, and I had thalassaemia. And I used to think 'why me', because my brothers were alright. They've got no problems and 'why me' like? So I think I used to get cross... I don't know, I really felt that I was different from other people, I'm not the same. (Farzana Azam, 17)

Some of the older respondents recognised that they often have idealised views of their peers' lives; several remarked that all young people faced problems. Rationality, however, offered little protection against these, mostly transitory, episodes of despondency and anger. With time, most recognised that asking 'why me?' did not help; instead, concentrating on the here and now, for most, proved facilitative (see also Atkin & Ahmad, 2000b, c). Questioning why they had the illness was a potentially destructive pursuit that undermined otherwise successful coping strategies and threatened their sense of normalcy.

### *Coping with uncertainty*

Uncertainty is a fundamental aspect of the narratives of young people with chronic illness (Mador & Smith, 1989). They find it difficult to come to terms with the uncertainties and limitations associated with their illness and this makes their coping strategies vulnerable. Even when their condition is stable, they may worry about what the future might bring. Our respondents constantly juggled the uncertainties associated with the illness with the possibility of 'relief'. This created a constant tension in their lives as they attempted to balance the consequences of a haemoglobin disorder and maintain a valued self-image. To this extent, coping strategies are adopted as part of a dynamic process and there are times when young people cope better with their illness than at others. This is sometimes in response to the specific medical consequences of living with their illness. The onset of the painful crisis, for instance, makes young people especially vulnerable. Bert Phillipson (12) was one of few children who had experienced a 'major' painful crisis between the first and second interview. This had a noticeable consequence on how he perceived SCD. When the first interview took place Bert had not had a painful crisis requiring hospital admission for two years. He was philosophical about his illness, suggesting it had little impact on his life. In the second interview he seemed totally overwhelmed by his illness and was especially concerned about how it would affect his future. He felt helpless and was worried about being dependent on others for the rest of his life. Following this, young people also get down by reflecting on the consequences of the illness for social relationships and self-autonomy. Most young people, for example, worried about forming peer friendships and being part of an 'in-group' (see Jenks, 1996). Having a haemoglobin disorder complicated this process. Absences from school for hospital appointments and admissions, disrupted social relationships and contributed to a sense of isolation. Aysha Habib (11) explained:

I come back from hospital. They [her friends] go 'oh you know we had so much fun, you missed it' and I wished 'oh, I wish I was there'.

Not surprisingly, there were times when young people were overwhelmed by the difficulties they faced:

I try not to think about it too much, yeah that's right, I don't like thinking about it really, because when I think about it I think, 'Oh my God'. (Wasim Jan, 17)

Attempts to forget about the illness and reduce its impact on life were only ever partially successful. There were still times when young people felt at the mercy of their illness. Anxiety, frustration and powerlessness undermined normal coping mechanisms.

Although such despondency was transitory, it may give the impression that the respondents found it difficult to cope with their illness. This would also seem to confirm the general literature, suggesting those who hold negative views of their illness had more difficulties in accommodating their illness than those who attempt to reduce the effect of the illness on their lives by playing down the negative aspects (Kliewer & Lewis, 1995). This, however, might not reflect dynamic nature of young people's coping strategies. Our findings show that although most young people go through periods of feeling 'engulfed' by the illness, such periods remain transitory, and are triggered as much by life circumstances and the responses of others as by the conditions. In support of this, we found no evidence of wholesale and long-term withdrawal from family and peer relationship among any age group. Aysha Habib, as noted, was concerned about her school friendships. In her second interview, however, which occurred three weeks after her last hospital admission, this assumed less importance. Coping strategies were thus successfully rebuilt and, on the whole, respondents were able to reconstruct their sense of normalcy. Even for Wasim Jan — who said he found it difficult to come to terms with the illness — despondency was temporary:

Depression, it stay in my heart. It's nearly ruined me. And then afterwards I get all right, like I told you, my depression, like it takes time to calm down. Like now, things are better for me. I'm calming down a bit... I just think good things and all that.

For most of the time, therefore, young people were able to balance their concerns about their condition with the need to live as normal a life as possible (see also Hill, 1994). They adopted coping strategies common to all young people, as they responded to the more general 'uncertainties' of 'growing-up' (see Frydenberg, 1997). Respondents emphasised the importance of 'just getting on with life'; adoption of various *normalisation* strategies helped this (see Hill, 1994). Things that marked out their difference had to be resisted (also see above). Normalcy, as Hill notes in relation to mothers of children with SCD, was often constructed 'apart from' having the condition. Madhuri Lal, who had thalassaemia said:

Although I've got this, I'm still really a normal person. *Apart from this*, it's just like I'm a person with this on the end. (our emphasis)

Alvin Kanhai, who had SCD, adopted a similar view:

I try and ignore it most of the time. That's why I don't tell people. It's like I'm just trying to get away from it. I'm just trying to pretend that I'm normal.

In particular, the relatively stable nature of thalassaemia facilitated such constructions of normalcy. Blood transfusions occur monthly and in hospital; chelation therapy too is contained in time and space, taking place at nights at home. Both can be seen to occur outside of 'normal life'. Jamil Rehman (17) explained:

You know you should basically live a normal life. The only thing is that like, you just going into hospital and having a blood transfusion, you're back out as then you're normal for a month and that's it.

Those with SCD were also able to sustain a sense of normality by separating the painful crisis from other aspects of their life. The painful crisis was the time these young people regarded themselves as ill. Thus normalcy was constructed in relation to boundaries of time, space and events, such as transfusions and painful crisis.

Playing down the negative aspects of their illness also introduces the idea of *positive framing* (see Hill, 1994). Most young people, maintained a sense of optimism and the illness was not a problem when things were going well:

I'd say don't think of it as something you are going to have it for life. Try to overcome it. Yeah. Yeah. Try to be positive, don't let it ruin you. (Amjad Javed, 17)

Such hope and positive framing was a valuable coping resource (see also Kliewer & Lewis, 1995).

Wishing to limit the impact of illness does not equate denial, but more a strategy for maintaining control over life and working with the condition (see Frydenberg, 1997; Hill, 1994). Several young people commented that constantly dwelling on what might have been is futile:

I think the more you think about it, the worse you end up but, the less you think about it, the better it is. I think you feel much better within yourself if you don't think about it. (Jamil Rehman, 17)

Young people were aware of their difference but attempted to work with the illness rather than against it. Several of the older respondents, for example, said it was important not to become angry and resentful. This is not to say that these older respondents have learnt to overcome the difficulties associated with their condition: sadness and frustration still occur. They cannot always transcend the vulnerability intrinsic to living with these conditions.

On the other hand, those aged 13–16 years often attempted to assert their 'normality' by confronting the limitations imposed by the illness. These respondents resisted anything that marked out their difference — elsewhere we have discussed the consequences of this resistance for treatment regimens (Atkin & Ahmad, 2000b,c). These young people, therefore, often rejected the need for chelation therapy or the importance of

‘looking after themselves’. Relationships with parents were more likely to be strained between these ages as a consequence of this. For reasons of space, we do not explore these issues here.

Young people recognised that successfully coping with the illness is important for others beside themselves. Many mentioned the impact of their illness on other family members; it was important to cope, for their sake. In this regard, guilt emerged as an important feature of their illness narratives; many felt guilty about the distress experienced by their families:

Well I think about the problem and how it’s affecting me and then I look around and see what I’m doing to others. Because like, if I’m sad then people just like, they get upset as well, ‘cos I’m not talking, like talking and everything. (Madhuri Lal, 12)

She gets so upset when I am having a pain and it’s not fair on her, like I don’t want to make her worry. Because if she’s upset I get upset for upsetting her. (Gail Thomas, 13)

Guilt, for most respondents, was a destructive force, capable of undermining their ability to cope. Fortunately it was usually short-lived.

#### *The importance of medical information*

Medical knowledge about the condition and its consequences was a useful resource for many (see also Hill, 1994). It could offer a sense of control, furnish preventive regimes and allow appropriate action during a crisis — however, as we have discussed elsewhere, knowledge was not the sole determinant of behaviour (Atkin & Ahmad, 2000b,c). Young people’s non-tolerance of chelation therapy, for example, was rarely based on a failure to understand its importance to their well being. Young people came to ‘hate’ chelation therapy because it offered a constant reminder of their difference.

Differences emerged in the value of medical information between those with thalassaemia and those with SCD. Young people with thalassaemia had a higher regard for medical explanations than those with SCD. The technology dependent nature of thalassaemia supported the medical model. Medical explanations did not make sense of all aspects of their illness, but their daily dependence on medical treatment made rejection of the medical definitions difficult. Medical information allowed a degree of control over their illness. The illness, defined in clinical terms, could be seen independently from ‘normal’ self-identity. However, young men more successfully employed such strategies of separating self from illness to construct ‘normalcy’, than women. Female respondents, as we shall see, were more likely to adopt alternative strategies.

Those with SCD less commonly adopted the medical model. This can be partly explained by the episodic nature of the SCD: its unpredictability and variability constantly undermined medical accounts. As Hill (1994) notes, medical accounts may even undermine the ability to cope by offering a discouraging prognosis while giving little effective control over the condition, especially the painful crisis. Recognising the shortfalls of the medical definitions and yet wishing to use medical knowledge to gain some control over SCD created unresolvable tensions. Such tensions, however, did not encompass treatment for painful crisis. All relied on medical interventions for relief from pain. However, as we note elsewhere, many delayed hospitalisation for pain relief as a consequence of a poor service and unsympathetic hospital staff (Atkin & Ahmad, 2000c).

More generally, the value young people accord to medical information reminds us that they do not wholly reject the ‘medical model’. The nature of their illness and the potential relief offered by medical interventions do not make this an attractive option. This is a general feature of chronic illness (Bury, 1991) and one that suggests possible limitation in using a ‘social model’ of disability to make sense of the experience of those with a haemoglobin disorder (see also Read, 1998). Many of the disadvantages faced by those with an SCD or thalassaemia are socially imposed and this is discussed below. Nonetheless young people also have to accommodate, for example, the need for regular blood transfusion and chelation therapy and their sense of physical pain as they make sense of their illness. We return to this in our conclusion.

#### *Religion and coping*

There has been a growing interest in the relationship between religious beliefs and ‘illness narratives’ (Williams, 1993; Kelleher & Hillier, 1996; Atkin & Ahmad, 2000b). Islam as a coping resource was especially relevant among the South Asian young people we interviewed (all but one of the thalassaemia sample were Muslim). This combined religion’s value as both a self-sustaining doctrine as well as its function in facilitating social support (see Hill, 1994). In practice, however, it proved difficult to separate out these two elements, although we will return to this distinction in our conclusion. Nearly all these young people saw Allah as a source of strength. No respondent was wholly disillusioned with Allah. Even when overwhelmed by their illness, respondents’ resentment towards the ‘unfairness’ of having the condition was transitory. Jamil Rahman (16) described how he sometimes gets angry with Allah:

I look back and I realise that I shouldn’t have said that. But it could happen to anybody and there’s far

much worse people than me. So I think of that as well at the end of the day.

About two-thirds of the sample reported that they prayed on a regular basis. Those under 13 tended to pray for a cure. With age, prayers focused more on gaining strength to cope with the illness. Belief in Allah and prayers were an important source of strength for these respondents.

Age, gender and ethnicity influenced how spiritual belief was utilised as a resource and this perhaps partly reflects access to the different types of social support offered by religious beliefs. Most younger children and girls had a somewhat passive acceptance of Islam. These younger respondents tended to follow family definitions of religious observance. Belief in Allah was not questioned and it was a taken for granted part of family life. Older boys — usually those over 16 — took a more active interest in Islam: often reading the Koran on a regular basis as well as attending religious worship. These older boys, with thalassaemia, often had more definite views of how their religious belief helped them come to terms with their illness. Concepts such as accepting one's fate and 'passing tests' sent by God helped make sense of their condition:

I just accept it, well I've got thalassaemia, and it's like everything else. Well obviously, I just believe it's a test, you know. God gives problems to those who know that, that can handle it and thank God for everything you've got. (Amjad Javed, age 16 years)

The idea raised by Amjad Javed, that Allah would only give the illness to those who had the resources to cope with it, was common to other respondents' illness narratives. To struggle against odds was a God-given obligation; dependency was a sin, 'an insult to Allah'. There were elements of this belief in nearly all the Muslim respondents' accounts. This obligation to do the best for oneself also encouraged adherence with treatment among the older respondents:

If I don't put the pump on, you know I'm committing suicide. Committing suicide is the highest sin, you have an obligation to keep yourself alive. I take that as an obligation. (Ashiq Javed, 18)

Those with SCD (mostly of Christian backgrounds) less commonly adopted religion as a coping resource. Religion seemed to have less relevance in their day-to-day life, but an important resource to some. Christianity was more likely to be used by younger children — usually those under twelve. These younger respondents prayed for relief from the consequences of the illness. Paula Grant (11), one of the few who explicitly drew strength from her belief in God, explained that she did not worry too much about the future because it is in the hands of God. However, the unpredictable nature of

SCD meant that this relationship with God was far from straightforward. Paula felt that most of the time God did listen to her, but some of the time she was ignored. For most, faith remained a resource to be utilised when needed. About half, for instance, prayed to God when they were in pain. Gail Thomas (13) asks God to "Please help me get better. Help me get better."

Several respondents maintained some sense of reward and punishment. They felt if they were generally good they would not have a crisis; to have a painful crisis in spite of good behaviour would be unjust. Although not explicitly articulated in terms of religious values, as Turner (1987) observes, such approaches do require a belief in divine justice (see also Williams, 1993). With age, religion seemed to have less relevance — except during the painful crisis — and no young person over 16, even those who occasionally attended church — referred to religion as an important coping strategy.

#### *Social and emotional factors*

Social support is recognised as a valuable coping resource. At times, however, solitude and crying too are therapeutic (Twigg & Atkin, 1994; Hill, 1994; Frydenberg, 1997). Young people often sought social support to overcome the difficulties they faced, especially when they felt overwhelmed by their condition. Social support enabled them to talk about the illness, provided an alternative focus of attention. This response was especially popular among girls and younger children:

Because if I keep it as a secret, I would be crying inside of me, like if I got a, I'm sort of person, if I keep things to myself, then I'll keep on getting depressed and distressed. I tell my parents to get it out of my system. (Farzana Azam, 17)

Many of the older boys, however, did not seek social support and saw talking as futile; talking did not change the situation. Seventeen year old Wasim Jan, when asked if he talked to his parents or friends when upset or feeling 'down', replied:

Forget it man, I don't like it. I don't like it. Simple. There's no point. It's not going to go away.

Conversely, several respondents described the benefits of a good cry and feeling sorry for themselves. Again the acceptability of this response was gendered. Such an approach, often a short-term focus for their discontent, was more common among older female respondents:

Sometimes I just try to, I just sleep on it, I just depress myself even further and further and it might sound silly to you but it's my way of coping with things ... I just tend to put some music in and not joyful music, very sad music. And get even more upset and more, because it's usually in the evening,

you know, when I get down and cry myself to sleep and you know things are always better in the morning. (Ismat Javed, 19)

Older boys regarded such emotional responses as a threat to their masculinity; crying was thought to be inappropriate for their age and gender. Although many did cry, such a response engendered guilt.

Solitude was valued by many as a means of coming to terms with sadness over the problems they faced. Respondents valued solitude for its own sake and because they did not wish to burden others. As noted earlier, many felt guilty about causing distress to their parents or making it difficult for family members to get on with their lives. Kaneez Mirza (16) valued her mother's support when she was worried, but was aware that her mother has other children to look after and consequently, there were times when she kept her worries to herself:

I'd tell my mum but then it was difficult at home as well because there's be other kids as well. So sometimes I just bottled it up inside.

Young people also feel that no one else can understand what they are going through:

They say 'I can understand what you are going through'. But they can't understand it, because they don't have it. And that does my head in. (Leroy Gordon, 15)

### **Coping with the responses of others**

Respondents' relationships with parents were often ambivalent. Parents remained their best allies. Yet they were the site of many tensions and resentments, although elements of the young person's response can perhaps be found in all parent-child relationships (see Frydenberg, 1997). This is another reminder of how the experience of chronic illness is closely related to more general life transitions and the process of 'growing-up' (Midence & Elander, 1994). Two factors appeared especially important in this relationship. First, parents often became scapegoats for the respondents' problems, although respondents recognised the unfairness of doing this. Second, parental concerns about respondents' health and well being were often regarded as restrictive and setting them aside from their peers:

It's like me mates, when they are 16 like, their parents let them do what to do and I am about two years behind, or three years behind. (Rashida Rana, 14)

This 'infantilisation' was experienced by most of the respondents, and whilst they did not question parents' motives, they resented the consequences of this 'over-

protection' for their lives and relationships. Others complained that their parents sometimes saw only the illness and not them. These tensions existed against the backdrop of, for most respondents, strong and supportive family relationships where parental and family support was a great source of strength. As Paula Grant (11) noted about her mother: "You know, she's always there. That's why I love her."

Young people not only have to deal with personal relationships but also accommodate the disabling responses of those in the wider social network. Young people often felt those in their wider social network were insensitive to their concerns; this insensitivity was seen to be located in general ignorance about their condition as well as disablism, racism and sexism. From the young person's point of view all these influences became entangled and impossible to separate.

Given this, respondents resented having to deal with the incompetence, ignorance and bigotry of others. Such responses threatened their identity, and undermined their skills and potential. For this and other reasons, many were discouraged from disclosing their condition to others. In part they also argued that such disclosures must remain relationship and context specific. Ashiq Javed (18), who had thalassaemia, summed up others' ignorance about the condition: "Most people have problems pronouncing the word never mind knowing what it is." His brother, Amjad Javed (17) was concerned that some people think thalassaemia is contagious: "They think, 'I might just catch it, I'd better get away from here' ". A few mentioned that they had come across people who associated thalassaemia and SCDs with AIDS.<sup>3</sup> Older respondents, however, had learnt to accept this ignorance and were less affected by such responses than younger respondents. Most maintained a valued self-image by arguing that ignorance is the problem of others.

Perhaps of greater concern were the ignorance and unsympathetic responses of professionals and prospective employers. Health and social care professionals can be a significant resource for patients and their families alike (Twigg & Atkin, 1994). However, poor relationships with these professionals can be a source of stress, a particular problem when discussing haemoglobin disorders (Anionwu, 1993; Atkin et al., 1998; Dyson, 1999). Young people valued positive contact with health professionals and emphasised how well-organised, sympathetic and sensitive services helped them come to terms with their illness and maintain a 'normal' life.

<sup>3</sup> A few people with thalassaemia major are HIV positive — although none in our sample — as a consequence of infected blood transfusions. The association between haemoglobin disorders and AIDS, however, was not informed by this, but more by a general prejudice and ignorance which did not distinguish between different types of blood disorders.

Many commented on their good relationships with doctors and nurses involved in their care and particularly valued being able to talk to health professionals, not just about their condition but also more generally. For example, Fozia Ahmed (10), in recounting her favourite nurse in the hospital where she receives transfusion, barely mentioned the nurse's role in relation to the transfusion. Instead she enthusiastically talked about their discussions about the nurse's forthcoming marriage and her engagement ring. Thus professional competence was assessed largely in terms of the social skills and empathy rather than technical skills alone.

However, lack of knowledge among health professionals remained a major problem. Respondents expected medical interventions to provide efficient and effective symptom relief and were critical that this did not always happen. Many of their problems concerned the management of pain — a common difficulty for those with an SCD (Maxwell & Streetly, 1998). Several young people 'took charge' of their treatment in the face of poorly informed nursing and junior medical staff. Professional arrogance, expressed as patronising attitude and an undermining of young people's own expertise in relation to the condition, exacerbated this perception of poor service:

And like, they're dead funny and stand-offish and because they're doctors, think they know it all, and, they don't really. (Sharon Francis, 19)

This is a familiar theme in the lives of disabled and chronically ill people (Oliver, 1996; Ahmad, 2000).

Hospital staff's insensitivity to the young person's pain represented a serious problem (see also Midence & Elander, 1994) and features strongly in parents' accounts (Atkin & Ahmad, 2000a). Young people complained about the slow treatment of pain and professionals' unwillingness to take the pain seriously; worse still, they resented professionals' insinuations that they exaggerated their pain, made unnecessary fuss or were hypochondriacs.

The ignorant ones that don't understand and they think I'm a hypochondriac and like, they just, the way of talking to me and just like, I don't like the way they talk to me sometimes. I told some of the nurses, and there is one I'm thinking of that, I still had the pain and they were asking me if I was alright and I was saying, 'No it still hurts a bit', and she was not doing anything, just ignored me. (Sharon Francis, 19)

The inadequate treatment of pain has been attributed to racist myths and stereotypes (Anionwu, 1993). The stereotypes of ethnic minority patients having lower pain thresholds and being prone to addiction to powerful painkillers, for example, are shown to relate to the

poor treatment of pain in SCD (Stimmel 1993; Midence & Elander, 1994). Parents too had expressed deep concerns about the racially discriminatory treatment of their children; such practice was thought to be based on professionals employing racist stereotypes in making judgements about treatment options and to these being 'black' conditions (Anionwu, 1993; Atkin et al., 1998).

Disadvantages were also evident in the young person's engagement with educational provision. Like their experience of health care, many attributed their difficulties to racism and sexism as well as negative assessments of their condition. Most felt their illness had affected their academic progress. Respondents attempted to overcome the disruptions but were often disappointed by the response of their teachers, a feature of educational support for those with a chronic illness (Fuggle, Shand, Gill, & Davies, 1996). Schools seemed unable to accommodate difference and offer support to young people. Many felt that the teachers had 'written off' their chances of academic success:

I was getting some silly comments, like 'he ain't normal. [No matter] how hard do you try with him, he ain't going to pass, he ain't going to do this'. Things like that. (Jamil Rehman, 17)

Young people, however, felt these low expectations were not simply a reflection of their condition. Older Asian girls felt that teachers did not expect them to pursue a career, while African Caribbean young people felt that their teachers had predetermined ideas about jobs fit for 'African Caribbeans'. Some respondents took pleasure in proving their teachers wrong. Jamil was about to take four 'A' levels after having obtained 10 GCSE passes.

Finally, the older respondents complained of discrimination in employment and in dealings with financial agencies such as mortgage and insurance companies:

Just like employers think that you are totally ill, and they don't offer you job or even if you have a job and if you have to take time off, you never know you might lose your job. (Ismat Javed, 19)

Amir Jan (19) had recently got married. His attempts to obtain life insurance had failed and he feared a similar fate in obtaining a mortgage. To him, not being able to buy a house compromised his ability to support his wife and thus was a threat to his status as a married man. The social prejudices attached to having a haemoglobin disorder thus have important consequences in terms of making transitions deemed 'normal' for those without these conditions. This was a harsh reminder that their victories against the illness were perhaps more easily achieved than tackling the prejudices of the wider society. His younger brother, Wasim Jan (17) remarked:

Just when you think you are getting somewhere, you realise the battle is not over. You just get so annoyed and angry.

Racism was regarded as an important feature of the labour market; for some this was more debilitating than the effects of their condition. Antony Johns observed:

It's bad enough trying to find a job when you are black. When they find out you have a SCD, you have no chance, do you?

That respondents, especially the African Caribbeans with SCD, perceived racism to disadvantage them in addition to the discrimination they faced in relation to their conditions, is a sad indictment on society and institutions such as education, employment and health services. Husband has argued that ideologies of oppression feed off each other (Husband, 1996); thus one form of marginalisation may well have links with other forms of marginalisation. For these respondents, the marginalisation they experienced due to their illness was exacerbated by racial marginalisation and gender stereotypes. Indeed some African Caribbean respondents believed that racism presented a more insurmountable barrier than their condition and to this extent illness did not always dominate their social relationship with others.

## Conclusion

This paper has explored how young people live and cope with a haemoglobinopathy within the broader context of social relationships and life transitions. Many of the issues raised by our work are relevant to the general experience of chronic illness among young people. Chronic illness often makes social interaction perilous, potentially increasing 'dependence' on others and challenges a person's self-image. The narratives of those with a haemoglobinopathy reflect these concerns and young people do find their illness — both limitations and uncertainties — difficult to cope with. To this extent, their experiences are similar to those with other chronic conditions such as severe asthma (Lemaneck, 1990), cystic fibrosis (Geiss, Hobbs, Hammersley-Maercklein, Kramer, & Henley, 1992), rheumatoid arthritis (Anderson, Bradley, & McDaniel, 1985) and diabetes (Johnson, 1988).

Our discussion also illustrates, however, how ideas about the 'social model' of disability and illness can help us understand the experience of haemoglobin disorders, although as we have seen, its application is far from straightforward. Nonetheless, when discussing the difficulties faced by young people, it is important to avoid presenting young people as tragic victims at the mercy of their illness (Oliver, 1996). The illness does not dominate

all aspects of their life; young people have to make sense of life transitions in the same way as their peers. To do this, young people struggle to limit the consequences of the illness on their day-to-day life and creatively utilise resources and strategies to live their lives (Bury, 1991). They adopted various coping strategies, to varying degree of success, as they attempted to live 'normal' lives and maintain positive identities. Maintaining this sense of 'normalcy', however, created a constant tension in their lives. The seriousness and uncertainties of the conditions made their coping strategies vulnerable and there were times when they were overwhelmed by their illness. The vulnerability of coping strategies, however, was neither intrinsic to the condition nor to individuals' psychological makeup. We have discussed that life transitions, social circumstances and the discriminatory behaviour of others — as a consequence of both disability and racism — all threatened their ability to cope.

To this extent, the disadvantages associated with haemoglobinopathies are often socially imposed as young people find themselves excluded, because of the inflexible attitudes of the wider society (see Oliver, 1996). The existing dominance of medical models in discussing haemoglobinopathies sometimes obscures the importance of this wider context. At the same time, however, young people, as we have seen, do have to accommodate the complications associated with their prognosis. This does not invalidate the concerns raised by advocates of the social model. Nonetheless, the medical consequences of haemoglobin disorders cannot be ignored when making sense of the young person's narratives. The vulnerability of their coping strategies, for example, can be partly explained by complications directly associated with their illness. The pain associated with SCD is a serious clinical consequence of the condition. In the same way chelation therapy and blood transfusion are essential to the survival of someone with thalassaemia. Thus the nature of the impairment or ailment cannot be divorced from its personal and social consequences, something often underplayed in the social model of disability.

Relatively few ethnic or cultural differences were observed in young people's responses to their illness. The use of religion as a coping resource, however, suggests one such difference. As noted, the largely Muslim South Asian respondents gained considerable strength from their belief in Islam. The notions of God having given them the strength to cope and their obligation to do the best for themselves were empowering concepts which the older respondents found to be facilitative in understanding and living with their condition. More generally, the use of Islam reflects the importance of religion to the lives of many South Asian people. Christianity, although less likely to be used by our respondents, offered similar support. There were

also more general differences — as we have seen — in how young people negotiated independence and autonomy (see Atkin & Ahmad, 2000b, c). This, suggests that the social model of disability cannot be uncritically applied across cultures (Stuart, 1996). Ideas about independence and autonomy are ethnocentric and rarely take into account possible ethnic differences (Ahmad, 2000). Discussion about independence and the more general process of ‘growing-up’ among ethnic groups is not entirely straightforward. Young Asian people, for example, were attempting to express cultural assumptions in which they have become socialised, while at the same time needing to live within a ‘Western’ frame of reference. To this extent, establishing autonomy is as important to Asian and African Caribbean young people as their ‘white’ counterparts. Nonetheless, independence may have a difference connotation among different ethnic groups. There seemed, for instance, less of an emphasis among Asian young people on establishing a home separate from their parents compared to African Caribbean young people and their ‘white’ peers (see Brannen et al., 1994). Making sense of chronic illness occurs against this backdrop and cannot be divorced from other aspects of the young person’s life, especially the experience of negotiating life transitions.

Racism, in different guises, remains an unfortunate fact of life for minority ethnic communities; our respondents were afforded no immunity. It emerged as an important feature of their accounts and a potential threat to their ability to cope with the illness and build a ‘normal’ life. Others have also discussed racism as a feature of haemoglobinopathy (Anionwu, 1993; Atkin et al, 1998; Dyson, 1999). When perpetrated by health and other professionals, it denies people their citizenship rights and perversely turns the assumed facilitative relationship with professionals on its head: as opposed to underwriting young people’s and their families’ strengths, professionals effectively undermine their abilities to cope. Whereas we have highlighted the similarities between the accounts of our respondents and those with other chronic illnesses, racism sets our respondents’ experiences apart. This, however, does not suggest a reified relationship between ethnic identity and haemoglobin disorders and it is important not to conflate the effects of the condition with the effects of ethnicity (Dyson, 1999). This suggests the importance of being able to distinguish between the consequences of the condition, societal reaction to that condition and the racialised nature of that reaction.

Living and coping with a haemoglobin disorder is, thus, a complex and dynamic process. The ability to cope is located neither wholly in individuals’ personal strengths nor in the condition itself. Social and material resources, life transitions and the responses of society and its institutions, all impact on individual ability to

cope. As this paper shows, these young people’s struggles to construct ‘normal’ lives can only be understood in relation to this wider context.

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