

Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia

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Abstract

There has been increasing interest in the way parents cope with childhood chronic illness and a shift away from merely describing the 'burdens' of care. An emphasis on coping by introducing ideas such as co-ordinated, accessible and appropriate service delivery as well as empowerment raises important policy and practice issues for public health. This paper, by drawing on qualitative material from a project evaluating service support to families caring for a child with a haemoglobinopathy, examines how parents cope with their caring responsibilities. First, it discusses the general literature on how carers respond to their role, before examining the specific literature dealing with the response of parents who look after a child with a haemoglobinopathy. Second, it presents the empirical accounts of parents who care for a child with a sickle cell disorder (SCD) or thalassaemia within the context of this broader literature. The paper concludes that all parents found caring stressful and demanding, but accept that they have to cope with the situation for the sake of the child. Parents' contact with services is an especially important contributory factor to their ability to cope and parents described how services can both hinder and support their caring role. Appropriate professional support can help reduce stress and facilitate coping by offering information, financial help and emotional support. Unsympathetic responses from professionals, or their incompetence, however, meant that many parents identified service provision as part of the problem, potentially undermining their ability to come to terms with the condition.

Keywords: chronic illness, coping and ethnicity, family caregiving

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Introduction

Parents of disabled children can face considerable physical, emotional and financial stress (Baldwin & Carlisle 1994). More recently, however, research has begun to focus on exploring the ways families *cope* with the care of a disabled or chronically-ill child rather than simply describing the *burdens* of care (Beresford 1994). Such an approach has the merit of emphasizing the creative aspects of human agency and the facilitative role of resources; it does not present carers as passive victims of their circumstances nor reduce the role of the disabled person to that of a 'burden' (Zarit 1989). An emphasis on coping is also important in understanding how

services can best support parents, by underwriting the families' existing strengths and helping to minimize threats to existing coping strategies (Ahmad & Atkin 1996).

This paper, by drawing on material from a project evaluating service support to families of children with haemoglobinopathies (disorders of the haemoglobin, namely sickle cell disorders and thalassaemia), examines how parents cope with their caring responsibilities. Specifically, it discusses the impact of caring within the context of coping: the materials, resources and strategies at personal, social and professional levels, which are found helpful in providing care. First, we review the literature on coping resources and strategies.

Second, we present the empirical accounts of parents who care for a child with a sickle cell disorder (SCD) or thalassaemia within the context of this wider literature. In doing so, the paper raises themes central to public health. An emphasis on coping, for instance, introduces ideas such as co-ordinated, accessible and appropriate service delivery as well as empowerment. The empirical focus of the paper also discusses the influence of gender and ethnicity – including the experience of racism – on coping strategies and resources. As a starting point, however, we provide a brief clinical description of the two conditions.

Sickle cell disorders and thalassaemia major

SCDs and thalassaemia major are recessive conditions where individuals who inherit a 'faulty' gene from both parents develop the disease. In the UK African-Caribbean and West African people are at greater risk of SCDs than other ethnic groups. Thalassaemia is more likely to be found among people of Cypriot, South Asian or Chinese origin than the white population. The thalassaemia gene can also be found in people of African-Caribbean origin and White British people. There are estimated to be between 6000 and 10 000 people with an SCD and around 600 cases of thalassaemia in the UK.

SCD is an umbrella term that includes sickle cell anaemia, haemoglobin SC disease and sickle beta-thalassaemia. Clinically, those with an SCD are prone to specific problems. Under certain conditions, the red blood cells change shape, resembling a farmer's sickle. This causes blockages in smaller blood vessels resulting in: mild to severe pain (the painful crisis), anaemia, leg ulcers, stroke and damage to various parts of the body including the spleen, kidneys, the hips, eyes and lungs. Children are extremely vulnerable to strokes as well as serious and life-threatening infections, 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'. SCDs are variable, unpredictable and, at times, life-threatening.

A child born with thalassaemia major is unable to make a sufficient amount of haemoglobin and will develop a fatal anaemia in early childhood if not treated with blood transfusions every 4–6 weeks, for life. The body's inability to excrete excess iron following these regular transfusions results in another important characteristic of thalassaemia: iron chelation therapy. To rid the body of excess iron, patients inject themselves with a drug such as desferrioxamine (desferal), using a battery-operated pump. The infusion usually takes 8–12 hours per day, five to seven nights a week. Not

surprisingly, many affected people and their families find the regimens for transfusions and nightly injections restrict their lifestyles. Other complications of thalassaemia major include diabetes, delay or failure to enter puberty and other infections, such as hepatitis C, acquired through blood transfusions. In comparison to SCD, the prognosis of thalassaemia major is more predictable and the condition more stable, although early death through non-compliance with chelation therapy is common.

Haemoglobinopathies, childhood disability and coping

The ability of parents to cope with the psycho-social and financial consequences of caring for a child with a chronic illness is not directly related to the severity or the nature of the condition (Beresford 1994). The key factors, which facilitate successful coping, include early diagnosis and appropriate information, the availability of material and social support, and family dynamics (Baldwin & Carlisle 1994). Children with SCD and thalassaemia, for example, are reported to be better adjusted and to hold positive body images and identities if living in families which are cohesive, supportive and expressive; with adequate income for additional heating, clothing and travel (Midence & Elander 1994). A clear understanding of the condition on part of the person and their family is also crucial to effective care and appropriate use of services (Baldwin & Carlisle 1994): this is equally true of haemoglobinopathies (Midence & Elander 1994). Appropriate professional support can help reduce stress and facilitate coping by providing information and financial and emotional support (Sloper & Turner 1992, Beresford 1994, Chamba *et al.* 1998). This is important especially where good family and social networks are not present. However, negative and unsympathetic responses from professionals, reported in many studies on SCD and thalassaemia, can be anxiety provoking and exacerbate feelings of isolation, inadequacy and helplessness (Darr 1990, Anionwu 1993) and influence future use of services (Midence & Elander 1994). More generally, inadequate haemoglobinopathy provision may also relate to racism and culturally inappropriate responses, which further contribute to the vulnerability of parents' coping strategies (Ahmad & Atkin 1996).

The ability to cope is far from an individual gift: material resources, family support, knowledge of services and of the conditions facilitate coping. Health and social services therefore can play an important role in reducing emotional and material hardship experienced by many parents. A simplistic emphasis on 'coping' creates a danger of interpreting a parent's inability to cope, as an individual problem, rather than as a reflection

of inadequate resources or inappropriate services (Twigg & Atkin 1994). This, in turn, could have important implications for perceptions of care-giving among Asian and African-Caribbean people; especially since the practices of such communities are often interpreted as 'inferior' and subject to racist discourse (Atkin & Rollings 1996).

Approaches to care-giving and the response of the carer

The literature on family care-giving suggests some broader frameworks for understanding coping behaviour. Two responses are commonly identified: *engulfment* and *balancing/boundary setting* (Lewis & Meredith 1988, Twigg & Atkin 1994). These two modes of response represent ideal types against which to understand the carer's experience, and are not intended as absolute categories. Carers do not necessarily fall exclusively into a single mode, but often exhibit a mixed response or shift between modes at different times.

Engulfment occurs when the carer has subordinated his or her life to that of the 'cared for' adult or child. Caring becomes a 'destroyer', the centre of the carer's life, and the defining feature of self-identity. It is hard for such carers to distance themselves from the situation and their emotional identification with the child is often so close, that they find it difficult to separate themselves from the child's pain and suffering. Twigg & Atkin (1994) found an association between mode of response and observable 'burden'; the more severe the condition the more likely the carer would feel engulfed. The physical pain experienced by the cared-for person contributed to the likelihood of the carer feeling engulfed. This finding, of course, has particular relevance for SCD. Importantly, Twigg & Atkin (1994) also noted that even when observable 'burden' was low, carers could feel engulfed, especially if they felt guilt over the birth of a child with a disability. The engulfed response also appears to be gender-related with women more likely to feel engulfed than men (Lewis & Meredith 1988, Twigg & Atkin 1994).

The essence of *balancing or boundary setting* lies in having an element of separation between the carer and caring; with carers placing value on maintaining some autonomy (Lewis & Meredith 1988). For some, the most important factor in adopting this approach was adjustment to their caring situation. Others maintained their balance by setting boundaries around what they would or would not do. Twigg & Atkin (1994) suggest there is a relationship between time and the *balancing* mode of response. Some carers start by being engulfed but after a period of adjustment move to a more balancing response. Nevertheless, they noted that the resolution

represented by the balancing mode could be unstable and carers were sometimes thrown back into an engulfed mode by some events. Twigg & Atkin (1994) also noted that the balancing mode was more likely to be adopted by men; who seemed better able to protect their sense of autonomy than women.

Haemoglobinopathies and the response of the carer

The general responses adopted by parents, described above, introduce important themes, particularly since there is little literature specifically focusing on parents of children with haemoglobinopathies. Nonetheless, Shirley Hill's (1994) proposed model of coping based on the experience of mothers looking after a child with SCD also has some relevance to those looking after children with thalassaemia. As a starting point, Hill suggests that most mothers coped with SCD by constructing their own meanings of the disease: 'meanings consistent with their resources and values, and meanings reinforced by those in the support system' (Hill 1994, p. 155). Following this, she suggests five possible coping strategies: embracing the medical model; achieving mastery; normalization; positive framing; and religion.

Those who *embraced the medical model* accepted medical definitions of the disorder and focused on acquiring and using medical information about SCD as a means of gaining some control over the condition; a response also noted in chronic illness literature (Bury 1991). Interestingly, mothers who rejected the medical model of SCD were better able to reconcile themselves to SCD (Hill 1994): the unpredictable nature of SCD meant parents who adopted the medical model would be faced with situations where attempts to control the condition seemed to end in failure. The medical model, however, remains important in managing the condition, especially during a painful crisis, and this makes it difficult for parents to dismiss it completely.

Embracing the medical model could have specific relevance for thalassaemia, particularly since parents and children rely on routine medical intervention for survival. Families therefore have considerable investment in this model (Battiatto 1990, Darr 1990). The reasonably stable prognosis may also give medical accounts of the condition more credence (Ahmad & Atkin 1996). For SCD, however, Hill reports this to be a relatively poor coping strategy.

Achieving mastery aims at controlling the manifestations of SCD symptoms. Surviving hardships instead of trying to understand them characterized the coping approach of these mothers. Parents caring for a child with thalassaemia seem to adopt a similar response

(Darr 1990). *Normalization* is aimed at diminishing stigma and thus creating a sense of control. (Eiser 1990). It can take a variety of forms, including emphasizing children's 'normal' appearance; denying that many illness symptoms were actually related to SCD; as the dominant feature of SCD was considered to be episodic and time-limited painful crisis, seeing SCD as an acute rather than chronic condition; comparing their children favourably with others who do not have a SCD; and denying the accuracy of the diagnosis and prognosis (Hill 1994). Again, this response can be potentially adopted by parents looking after a child with thalassaemia (Darr 1990). Another coping strategy identified by Hill and associated with *normalization* was *positive framing and optimism*. While acknowledging the child's physical limitations, some parents stress that their child had other abilities that compensated for that loss (Hill 1994). Mothers also felt that having a child with SCD led to the development of special qualities and strengths in themselves, their children and other family members (see also Eiser 1994).

Finally, *religion* was a key resource for some mothers, enabling mothers to view dealing with SCD as enhancing their own spiritual growth and through prayers helping them with coping with the symptoms of illness. Hill's account, although applying to Christianity, could be equally relevant to people with different religious beliefs (Williams 1993, Kelleher & Islam 1996).

The empirical study

The findings presented in this paper are drawn from a qualitative evaluation of service support to families of children with an SCD or thalassaemia. The aims of the study were three-fold. First, we wished to examine both mothers' and fathers' perspectives on the nature and appropriateness of service provision for their affected child and relate these to the views of service practitioners and managers. As such the study would generate an understanding of the support parents find helpful and the difficulties experienced by those attempting to provide such support. The second aim was to provide an understanding of the co-ordination of haemoglobinopathy and related service. The third and more general purpose of the study was to develop recommendations for improved provision.

The evaluation was based on in-depth qualitative interviews with 37 parents (17 couples) of a child with thalassaemia and 25 parents (eight couples) of a child with an SCD. The eventual sample included 34 mothers, 25 fathers and three guardians (an uncle, brother and sister-in-law), drawn from the records of health professionals in seven localities in the North of England. Although it is difficult to be certain, we believe this

represented a total population sample of affected children in these areas. The uncertainty relates to the lack of central records for haemoglobinopathies. We opportunistically discovered, for example, one case of SCD that was not known to health professionals. As thalassaemics are transfusion dependent, we can be more confident that health professional records include all cases in a their locality.

Eleven of the families with a child with an SCD were Caribbean in origin, one was Indian, one Algerian, one Nigerian and three were of mixed ethnic origin. Of the thalassaemia sample, 15 families described their ethnic origin as Pakistani, one as Indian, two as Bangladeshi and two as East African Asian. Fifty-one interviews were then undertaken with key service providers, managers and commissioners. (Their accounts are not included in this paper in any detail except for contextual purposes where appropriate).

The approach to evaluation adopted by this project required a methodology that could reflect the plurality of social reality and accept that different stakeholders utilize and adapt different discourses in their attempt to make sense of the world. To accommodate this, the empirical component of this evaluation was qualitative, using in-depth interviews. Such a method can provide a basis for understanding the complex behaviours and interactions, within a contextual framework, thus enabling particular contingent situations to be explained (Gubrium & Silverman 1989). This approach is particularly recommended for the study of the ways individuals express their understanding of themselves, in the context of their biographical, social, cultural and personal circumstances (Mishler 1986). A topic guide identified a number of key themes developed from a review of the relevant literature on haemoglobinopathies, family care-giving ethnicity and welfare, discussions with key informants and advice from an 'expert' advisory committee. For example, an important theme of our analysis was exploring the different coping strategies used by parents. This meant taking the various models of coping, such as that proposed by Shirley Hill (1994) and translating it into specific questions about the parents' care-giving role. Interviewers and interviewees were matched according to language and gender. Nineteen interviews were conducted in Punjabi, one in Bengali, and one in Urdu. Under each topic, particular probes were included to make the conversation more focused, detailed and concrete. All the interviews were transcribed and organized according to analytical headings, including one on coping. Interviews in languages other than English were fully interpreted onto another audiotape. Following accepted conventions of qualitative analysis (Gubrium & Silverman 1989), information was taken from the transcripts and transferred

onto a map or framework, allowing comparison by theme and case. The respondents' accounts were specifically organized by categories and subcategories, suggested by the topic guides as well as new categories that emerged from 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 generalizing 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. Analysis could then begin to define concepts, account for patterns and ranges, establish linkages and give explanations. The empirical material is organized under three main headings: coping with a haemoglobinopathy; the vulnerability of coping strategies; and service provision, coping and racism. In the discussion below all names of individuals and places are pseudonyms.

Coping with a haemoglobinopathy

Nearly all the parents agreed that caring for a child with a haemoglobinopathy was, at times stressful and demanding. Mrs Prince, whose child had an SCD, summed up the feelings of most parents:

It can be quite wearing looking after them ... And it's not just the worry, it's actually your life stops and you can't do anything else.

Parents, however, recognized that they have to cope with the condition, for the child's sake. Shakeel Islam, whose son has thalassaemia, reflected the view of most parents: 'We have to do it ... What else can you do?'

Mrs Wynn, who has a son with an SCD made a similar point:

I have to just shrug my shoulders ... and at the end of the day, I can't wallow in self-pity. You've got to take whatever life throws at you.

Most parents described how they learned to cope with the condition over time. Mrs Francis described how she initially found caring for her daughter with an SCD extremely stressful. Later, as she adapted to the condition, she realized that she had to be strong and 'deal' with caring for her daughter:

I just dealt with it, I suppose I'm just made that way, I don't make it, I don't put it down as a burden, I just struggle through with it. I used to, but you have to get on with it, be strong. Oh yeh, sometimes I'd be narkey, I'd be tired but I'd just have to get up and do it the next day.

Many parents therefore accept their caring role because they feel there is no alternative. Getting on

with looking after the child, without questioning why they were doing it, represented an important coping device for parents. Balbir Singh, whose son had thalassaemia, said:

I don't worry too much now. I take this day by day. What we're going to do the next day. I don't think like in 2 weeks time what's gonna happen. No. I take it day by day. See how he is, if he's alright we go out, if he's not alright then we don't go out. I try to keep him happy as possible, just take it step by step. That's what I'm doing now.

Other parents took a similar view, and emphasized the value of trying not to worry too much about the possible consequences of thalassaemia or SCD, but deal with problems when they arise. Separating what needs to be done into discrete 'step by step' tasks and 'taking each day as it comes' offered some protection against being *engulfed* and seeing the caring responsibility as a never-ending burden. This was not an expression of denial but a practical response to a potentially traumatic and uncertain future.

The importance of accepting their caring responsibilities and coping with things as they happen – on a day-to-day basis – offered some parents some control, or in Hill's (1994) terms, *mastery over the condition*. Parents who focused on their ability to manage, usually tried not to provide an explanation of the condition. Finding explanations was not the most important task; what was important, from their point of view, was that they could handle it. Such a coping approach is often supplemented by the parent emphasizing the normal aspect of the child; in other words *positive framing and normalization* (see above). Parents tended to use such approaches simultaneously. Many, for example, attempted to emphasize the normal aspects of their child's life and play down his or her difference. Some also defined 'health' in a way that excluded the child's condition, allowing the child to be regarded as 'healthy' in relation to their condition and ailments. Mrs Leigh, for example, remarked that her son with an SCD was the healthiest of all her children:

I mean he's the healthiest child in all of them really, to be honest. Honestly. I mean, rest of them's off with cold, vomiting, off school and he's always the one that never gets it. I says 'I'll have to start you lot on folic acid daily'.

In emphasizing the 'normal' aspects of the child's life – and having a definition of health that excluded their haemoglobinopathy – the manifestations of their child's condition could be minimized. In thalassaemia, medical treatment could be separated from the child's 'normal' life. Blood transfusions occurred in hospital and use of the infusion pump usually occurred at home in the evenings, when the child had finished their

daily activities. Such compartmentalization of the consequences of the condition allowed the enhancement of the child's 'normal' life. Some parents felt that their child had other attributes that compensated for them having a long-standing illness or emphasized their 'normality' or 'well being' in other areas. Robina Javed – who has three children with thalassaemia – praised her children's intelligence and achievements:

Thank God, our children are very patient and intelligent. We thank Allah that they are okay in all the other areas ... Allah has given them extra as far as intelligence is concerned. Allah has favoured us in something else.

Her children were all good scholars; qualities of which she was proud. Other parents emphasized their child's special strengths and skills such as bravery, or heroism. Mrs Wynn, for instance, was proud of her son's independence. Several parents particularly praised the maturity of their child and attributed this to the illness.

Religion represented another important coping device for many families. Two African-Caribbean mothers, for example, cited their Christian faith as an important source of support. Mrs Hunter, for example, said that although on occasions she could not cope, God was her strength:

I see God as my strength really. We don't go to church but I do believe in God. I do pray and I do believe that he's helped me through it really.

Religion was a particularly important coping strategy for Muslim families. (The sample included 20 Muslim families: 17 of children with thalassaemia and three of children with an SCD). All but two Muslim families emphasized their faith in Allah. Nurun Nissa Hussain remarked: 'Allah gives us the strength and courage to carry on'.

Mr Alvi, like many other parents, saw his caring role as a duty given by Allah. Several families specifically remarked that if Allah gives one the condition he also gives them the strength and resources to cope with it. To this extent, Rashida Habib, said that Allah gave the family strength:

We just keep our faith in God. He's the only one that can do anything anyway and there's no point us just worrying ... and worrying on and on about it. Because on our own we can't do anything. Allah gave us these two children.

This belief in Allah, however, did not encourage despondency or dependency. Families combined a trust in Allah with the need to provide the best care and treatment and doing the best they could for their children. To this extent parents realized the importance of taking responsibility over their own lives rather than leaving things to fate. No parent had a naive

view that everything would turn out all right without a concerted effort on their part or that there was no point in trying to improve things as their fates were already decided. This explains why religion was often used in conjunction with other coping strategies.

The parents' belief in a cure for thalassaemia reflected their utilization of different coping strategies. The severity of the condition meant that many parents hoped that a cure can be found. Many parents, for instance, prayed to Allah for a cure and also had a high regard for Western medicine. The belief in a cure therefore reflected a combination of the strength of religious faith and trust in biomedical forms of knowledge.

Parents of a child with thalassaemia had a particularly strong trust in the medical model. Medical knowledge was seen to offer both the opportunity of control and of cure. The reasonably stable prognosis of thalassaemia and the child's reliance on medical procedures tended to give the medical discourses credence. *Embracing the medical model*, on the other hand, was only partially adopted by families, whose child had an SCD. Several parents did attempt to use medical information and follow precautions to gain some degree of control of the condition. These parents, however, were usually aware of the limitations of this approach and it rarely formed a dominant part of a parent's approach to coping.

Family relationships and coping

The coping strategies mentioned above were used by all parents, regardless of gender. There were no parents who played no part in the care of their child. To this extent parents could support each other and help each other cope with the consequences of their child's illness. Mothers, however, were usually responsible for the day-to-day care of the child. This was expected by both mother and father. Nonetheless such a division of labour provided another coping strategy available to some fathers, that of relying on the mother to cope. Several mothers, for example, mentioned that their partners could not stand to see their offspring in pain, and therefore often needed to leave the house for respite. Mrs Garner, for example, remarked:

I don't know, I don't think he likes the pain, I think it gets to him, he runs out the door when she's in pain, he can't take it, you know what I mean. But he's always saying, you know, just make sure, have you given her this, have you given her that.

In most cases, mothers accepted their partner's response and saw caring as their own responsibility. In some couples, however, the father's attitude was causing problems and undermined the mother's coping ability. Several mothers, for instance, felt their

spouses did not take the condition seriously. Farzana Islam, remarked:

Well there's more pressure on myself and my husband and on our marriage. The fact that he hasn't taken the illness seriously has actually drawn us apart. He's not supportive to me.

Relying on the other partner to cope, however, was not always a male strategy. In some families, the mother relied on the father to perform some technical tasks associated with the condition. Several mothers, for example, could not cope with injecting their children and although they were responsible for all other aspects of their child's care, they relied on their partners to perform this task. Rashinda Habib mentioned that she did not have 'the courage' to inject her son and consequently her husband had to do it.

Many parents – African-Caribbean and Asian – mentioned the importance of support from other family members. This support was practical, emotional and financial and usually helped the parents cope with caring for their child. Several mothers, for example, mentioned they could rely on their mother or sister to care for their other children when they had to attend hospital appointment or stay overnight with a sick child. The extended family's involvement, however, was not always supportive. Alya Saeed felt that her husband's family, with whom she lived did not understand the condition. She had particular problems with her mother-in-law:

I feel like I am coping on my own When I am low I think 'Why don't my mother-in-law listen to me?'

Several other Asian mothers criticized the role of their mothers-in-law. These mothers felt that their in-laws had attempted to gain control of the situation, dictating to the mother what she should be doing. To this extent, these extended families performed a policing rather than a caring role and this could undermine a mother's coping ability. This is an issue raised in other studies of family care-giving in Asian households (Chamba *et al.* 1998).

The vulnerability of coping strategies

The nature of the SCD and thalassaemia made coping strategies vulnerable. Even when the child was relatively well, parents often worried about what the future might bring. Mrs Hunter – whose child has an SCD – described it as a constant pressure that would never go away:

I mean it's always there. You never know what's round the next corner. You get on with life the best you can but you know it can be turned upside down, at any moment.

Parents therefore had to constantly juggle the uncertainty associated with the condition with the possibility of relief. Worries about the future, however, were not constant and, although they were never entirely forgotten, most parents could often push them to the back of their minds. Mrs Leitch, whose child had an SCD, summed up many parents' coping strategies by saying that she tried not to worry about the condition unless something happened and took 'each day as it comes' (also see above). Consequently, for most of the time, the majority of the parents were able to *balance* their worries about the condition with the need to live as normal a life as possible. The importance of maintaining a balance between getting on with life and worries about the future was also felt important in helping the child cope with the condition. Mrs Wynn, for example, remarked:

I'm not sure, it wouldn't do Alex any good, seeing me worried all the time. I mean he's got enough to cope with. You know what I mean.

This balance when broken by certain life events made the parents feel *engulfed* by feelings of anxiety, frustration and powerlessness. It was during these stages that the parent would ask 'why me?' as they attempted to come to terms with the condition. At times therefore most parents do find it difficult to cope – but for most this is short lived. However, most parents criticized services for not recognizing their needs when the consequences of caring got too much for them, particularly those who did not have close family support.

In SCD, the onset of a painful crisis, for instance, often brought on a sense of engulfment. Parents described pain as the most difficult aspect of caring, first, because of the practical disruptions it caused, and second because of the parents' own distress at seeing their child in pain. Rukshinda Daudji's account was typical:

I get more worried. I always cry, I start crying ... I don't know what to do so I always cry, if she's poorly I always cry.

Her distress was heightened as she often 'protected' her husband as well as her own parent by not sharing her concerns and worries. Her husband, she felt, found it very difficult to accept their daughter's pain and she therefore shielded him as much as possible. Her parents – who were elderly and poorly – became very distressed by her daughter's painful crisis. Although her husband and parents were supportive, she received little practical help when she needed it most – worse, she controlled her own emotional distress for fear of causing distress to her family. Other mothers mentioned similar problems and this again undermined their ability to cope. Fathers, however, rarely faced this problem.

In the case of parents who looked after a child with thalassaemia, the use of the infusion pump and monthly blood transfusions offered a constant reminder of the condition's severity. The use of the infusion pump caused pain to children; many parents found this distressing. The monthly transfusions caused considerable disruption and anxiety. Balbir Singh, for instance said that she always felt depressed when her child was due his transfusion:

I have to admit, sometimes it gets to you. Sometimes you feel like [you are] the only person in the world who has to cope with these problems. You can't help it.

Parnika Nehru became engulfed when her child resisted infusion therapy:

I mean your child's screaming and doesn't want anything to do with the needle. You're bound to think 'what have I done?'

Farzana Islam remarked that inserting the needle, hurt her as much as the child:

If the child has an injection in his thigh, first the mother has an injection in her heart.

Most parents, however, are able to re-build their coping strategies. As we have seen, most appear to adopt a balancing mode and only become engulfed during particular episodes. There was only one mother whose child had an SCD, who could be said to be *engulfed* or overcome by the condition most of the time. Mrs Hardin, whose daughter was diagnosed as having SCA at the age of 11 years, said:

I can't get it out of my head. I worry all the time, every-day. It never goes away. There's not a minute goes by that I don't think about it.

Engulfment was more common amongst mothers whose child had thalassaemia and was the dominant experience amongst five mothers. In all five cases the mothers complained about the lack of support from their spouses and other family members. The lives of these five mothers were dominated by the condition and they could not see how their situation could be improved. Fatima Mian said that she makes herself ill worrying about the condition:

I'm so more worried about his illness, crying often in the night, not sleeping well. Daytime is okay but still worrying in the daytime.

Three mothers were being or had been treated for depression. Saeeda Khalid, for example, described a long history of depression which she attributed to her

son's condition. Shazia Sharif was also being treated for depression and often had to get out of the house when the condition got too much for her:

I, little bit fed up, you see, then I just go out but in this cold weather where can I go, you know. I just get cold but I need to get away. It's too much. Then I just sit here and then I just do ironing, but sometimes I just leave the ironing like this and the dirty house you know. Why bother?

Parents of children with SCD and thalassaemia described similar techniques for coping, when the consequences of caring overwhelmed them. This, as we have seen, means taking each day as it comes. Most also commented on the importance of creating some space of their own in addition to the above strategies. This enabled them, momentarily, to forget about the pressure they face. Mrs Johns explained:

Sometimes it does get too much. You just have to go to another room and sit quietly by yourself. Otherwise you would lose it.

Others described the benefits of 'a good cry'. Mrs Hunter said:

I just cry. I just have a good cry. If I don't have a cry I think I break down.

Other parents, such as Mrs Adams, say they have a good shouting match with their partner. This again was seen as an important safety valve. A common response of fathers was to leave the home and escape the demands of their child's pain. However, as we have seen, this placed the responsibility on mothers.

When the situation seemed unbearable most parents have people they can talk to. These usually include their partner, sister or mother. Mrs Sol, for instance, emphasized the value of talking to her husband. Other mothers prefer to talk to their own mothers or sisters. They felt their husbands were too closely involved in the situation. Other parents, however, did not have anyone they can talk to: either because no one was available to talk to or because parents did not wish to 'burden' others. As noted above, Rukshinda Daudji could not discuss the situation with her husband or parents because they got too upset. Similarly some mothers, although desperate for someone to talk to, felt unable to burden other people with their problems. Several parents felt that wider family members were unsupportive and reluctant to discuss the situation. Two families had no other relatives in this country and did not want to talk about the situation to people outside the families. Other parents, however, did not feel the need to talk. These were usually, but not exclusively, fathers. Mr Hunter's response was typical: 'What's the point. They can't do anything can they?'

Mr Evans, remarked, however, that such a response caused problems with his wife, who cannot understand his reluctance to talk.

Service provision, coping and racism

Parents' highlighted both facilitative and debilitating aspects of service provision. Parents specifically mentioned two difficulties, associated with their contact with service provision, that affected their caring role. These included a lack of information and the incompetence and unsympathetic approach of health professionals. Parents, for example, criticized professionals for not knowing enough about their child's illness and seeming disinterested in their child's suffering. These problems were seen to make their caring responsibilities more difficult than they need be and at times contributed to the parents' sense of engulfment.

Many of the problems faced by these parents are, of course, similar to those faced by parents who look after a child with another chronic illness (Sloper & Turner 1992, Baldwin & Carlisle 1994, Beresford 1996). This has important implications for policy and practice. A positive commitment to improving services for parents looking after a child with a chronic illness would benefit those from minority ethnic groups. Nonetheless, their association with minority ethnic populations often adds another dimension to the parents' difficulties (Anionwu 1993). The failure to acknowledge the existence of a multi-ethnic society, for example has resulted in an inability to respond to haemoglobinopathies in an equitable and timely way (Ahmad & Atkin 1996). This perhaps explains why even community activists in metropolitan areas with the highest prevalence of chronic illness, have had an uphill struggle to convince health authorities of the need for resources to develop provisions (Atkin *et al.* 1998). Racism therefore can explain the low priority and poor coordination of haemoglobinopathy provision and professionals' negative attitudes (Bradby 1996). Several studies exploring haemoglobinopathy provision agrees and associates the problems experienced by parents with racism (Ahmad & Atkin 1996). Few parents, however, explicitly associated the two; although notions of racially-motivated unfavourable behaviour, negative attitudes and disinterest in a 'black' condition were implicit in many parents accounts. For example some parents – mainly African-Caribbean – felt that if haemoglobinopathies affected more white children, there would be better service delivery. Mrs Prince compared the services available for what she regarded as a 'white' genetic condition, cystic fibrosis and those available to those with an SCD. This, however, is as far as many parents would go.

This is not to dismiss racism as a major contributory factor in inadequate and poorly resourced haemoglobinopathy provision (Anionwu 1993), it is more a reflection of the diffuse and subtle way institutional racism impacts on the lives of minority ethnic groups living in the UK. Inadequate pain control, for instance, is a constant and worrying problem faced by parents looking after a child with SCD. Racism can contribute to poor pain control and means that one of most distressful aspects of the illness remains untreated. Stereotypes of minority ethnic patients having a lower pain threshold are rife in the health services (Bowler 1993) and may be used to justify a lack of pain relief (Atkin *et al.* 1998). The lack of treatment can also be justified by another racial myth. Some people with SCD require powerful drugs for the control of pain. However, some doctors worry about their African-Caribbean patients becoming dependant on drugs (Stimmel 1993) and this can contribute to the significant under-treatment of pain. There is no evidence to suggest that addiction to powerful pain killing drugs is a significant problem among SCD sufferers (Midence & Elander 1994). More generally, as Hurtig & White (1986) have pointed out, the medical myth is that pain in SCD is 'manipulative'; and can 'serve to demand attention at best and drugs at worst'. Equally some Pakistani parents felt that practitioners' implicit or explicit criticisms of consanguinity was influenced by their generally negative attitudes towards South Asian cultures (see Ahmad 1995 for an account of medical discourse on consanguinity). This was also perceived by parents to be related to poor service delivery. Although much of this criticism related to issues around diagnosis and genetic counselling, it affected their general feelings towards services.

Information

Parents criticized health professionals for failing to provide basic information about the condition. Some related professionals' lack of knowledge to SCD and thalassaemia being 'black' peoples' conditions. Other complaints included the inability of health professionals to realize the changing information needs of parents. Parents, for instance, often require information relevant to their immediate experience. Like many parents, Mrs Garner commented that it was no use being told about a painful crisis when the child was born; the information was only of value when the child was going through a crisis. Generally, parents felt ill-prepared to deal with the consequences of the condition – especially as it impacted on a developing child – and their care-giving responsibilities as they did not know what to expect. Parents also commented on the difficulties of obtaining information about the support available to

them. Mrs Francis was especially annoyed at not being told about what services were available and felt it wrong that she should have to find out such things on her own with little or no support or guidance. Like many other parents, she felt the lack of information on the support available to her added needlessly to her caring responsibilities – lack of information about the condition and services is, of course, a common theme in the literature on children and caring (Baldwin & Carlise 1994).

The problem of obtaining information was compounded for those who could not speak or understand English. Language support was generally poor and represented another example of institutional racism. Several parents, for example, complained that information was only available in English. In some cases family members were used as interpreters and, although acceptable to some parents, others objected to the practice. In some cases affected children or their siblings as young as 8 years old, were expected to interpret complex medical information. Many parents objected to this as they felt it undermined accepted parent–child relationships. Parents felt that the child should not be placed in this position and worried about the child’s gatekeeping role. Some parents, for example, felt that important information might not be passed on. Parents were also aware that children might want to protect them. Several mothers also pointed to the problems their husbands faced in simultaneously translating distressing information and coming to terms with it themselves. Fathers confirmed these problems and had particular difficulties in deciding how much they should tell their non-English speaking wives: often they wanted to ‘protect them’ from information deemed upsetting. However, this created another problem as it left mothers without important information about thalassaemia; information important for understanding, coping and caring. Problems still occurred when interpreters were used. Most interpreters, for example, had little specialist knowledge about thalassaemia and therefore their competence to translate clinical information and treatment procedures was at times questionable. This created misunderstandings. Other parents felt the process of interpretation inhibited discussion, making it difficult to ask questions. Interpretation was particular problem for some smaller minority groups. A Bengali speaker, for example, was expected to make do with an Urdu/Punjabi speaking interpreter. Her protest that this was no help was regarded as ‘unreasonable’ and ‘ungrateful’ by the consultant treating her child.

Competence of health professionals

More specifically, a sizeable proportion of parents felt unable to trust the care offered by many health

professionals and social workers. This lack of trust was a particular problem when a child was admitted to hospital. Instead of having faith that professionals would do the best for their child, parents felt they had to check on the actions of health professional to ensure their child received adequate care. Razia Khanum, whose son had thalassaemia, always stayed with her son when he was in hospital. She described how she would not eat or drink when her child was admitted to hospital, to ensure she would not have to go to the toilet which would mean leaving the child’s bedside. These anxieties were not necessarily associated with parent’s sense of over-protectiveness; many of these parents cited concrete examples where inappropriate care was given and many were confirmed by the consultant physician. Specific examples included ignoring the child’s pain; giving insufficient pain relief and directly contravening established protocols; leaving sterilizing fluid in tubes used for blood transfusion; and using out-of-date blood. Such experiences led many parents to say that the most important thing they had learnt was knowing how to deal with service providers and, in particular, the value of being assertive. Many parents’ experiences of dealing with some professionals were stressful and added unnecessarily to the problems they faced in caring.

On the other hand, sensitive service support could help the parents cope better with the condition, especially when parents lacked appropriate family support. In this respect, two-thirds of all parents mentioned the support of specialist haemoglobinopathy workers in helping them cope with the condition. Several localities employ specialist health professionals to provide haemoglobinopathy services. There is, however, little consistency over the use of job titles. Sometimes they were known as haemoglobinopathy counsellors, health promotion nurse specialist or project workers. They are usually employed by community health trusts. Nearly all those who worked with families of children with thalassaemia were Asian women with language skills in Asian languages. Parents felt they could contact these workers in times of difficulty, as well as for information and advice. Razia Khanum, who distrusted hospital staff, described the worker she had contact with as ‘my guardian angel’:

Lucky she came round when she did [the specialist worker] as I’d gone through hell before. Honestly, I mean she is heaven sent that women. Yeah, I couldn’t have coped without her.

For this mother, the support from the specialist worker was crucial in coping with her child’s care. Many parents shared these sentiments. Contact with the specialist workers was especially valued by

parents if the parents felt that their own family did not understand the condition. This meant the parent had no other person to talk to about the condition, and without the support of the specialist worker, could feel isolated, lonely and unsupported. These specialist workers also offered practical advice, social and emotional support and information on benefit entitlement. An added advantage for many Asian families was that these workers shared their linguistic and cultural backgrounds, thus giving parents more confidence in the support. More generally it was important for parents to know there was someone they could talk to who understood the condition and the problems they faced, especially given the negative experiences of service provision, expressed by some parents. This reassured parents and helped them cope better with the condition. In particular, these workers made it possible for Asian mothers, many of whom did not speak English fluently, to have direct access to information and other support which facilitated coping.

Conclusion

There has been increasing interest in the way parents cope with their child's chronic illness and a shift away from merely describing the 'burdens' of care (Beresford 1994). As a reflection of this, this paper described parents' experiences of coping with a haemoglobinopathy within the context of the more general debates on coping, family care-giving and haemoglobinopathies. In doing so, the paper raises themes central to public health. As we have seen, these include the value of co-ordinated, accessible and appropriate service delivery as well as the importance of empowerment and family-centred provision. To this extent the paper presents a user-based commentary on how services can best support parents by underwriting their existing strengths and helping to minimize threats to their coping strategies.

As a starting point, service commissioners and health professionals need to understand how parents cope with their role and then work with them to ensure their coping strategies are sustained. In coping with their child's illness, parents emphasized the importance of getting on with daily living; a theme common in other studies on family care-giving (Twigg & Atkin 1994). Parents therefore focused on their ability to manage and *achieve mastery* over the condition (Hill 1994). Such a coping approach is often supplemented by the parent emphasizing the normal aspects of the child's experience as well as special strengths that compensate for the condition. The use of *normalization* and *positive framing* by parents, however, was not a form of denial but an attempt to manage the condition.

The main differences in the coping strategies used by parents of a child with an SCD and those children with thalassaemia, occurred in the extent to which they *embraced the medical model* and related their *religious beliefs* to their caring role. Parents of children with an SCD only partially embraced the medical model to help cope with the condition. This reflected their general mistrust of medical explanations and health professionals, but also the variable and episodic nature of the condition which made it easier to dismiss medical explanations. Parents of a child with thalassaemia, on the other hand, were more likely to accept medical explanations of the condition, regarding medical knowledge and procedures as essential to their child's well-being. The extent to which this is a reflection of the difference between conditions or is a cultural difference between African-Caribbean and Asian parents can be debated. However, we suggest that the difference may be related to the conditions. Religion was also more likely to be adopted as a coping strategy by parents of a child with thalassaemia than by those of a child with SCD. This seemed to result from the different religious backgrounds of the two samples. Nonetheless the use of religion was not totally absent from the SCD sample; parents who were practising Christians and Muslims emphasized how their beliefs offered an important source of support. Most parents of children with thalassaemia were Muslims and their religious belief emerged as an important coping device. Other studies also note this (Currer 1986, Kelleher & Islam 1996). All but two families emphasized their faith in Allah and a belief in their strength to cope with the condition. Consequently, despondency or abdication of responsibility was not a necessary part of 'fatalism'. This shows the need to guard against simplistic and reductionist accounts of 'fatalism' so commonly associated with Asian populations (Qureshi 1990).

However, the nature of the two conditions as well as shortfalls in service and family support made the parents' – and especially the mothers' – coping strategies vulnerable. This is a general feature of the literature on haemoglobinopathies (Darr 1990, Midence 1993, Atkin *et al.* 1998) as well as the wider literature on family care-giving (Twigg & Atkin 1994). Consequently, there are times when parents felt *engulfed* by the condition and unable to cope. This was more common among parents caring for a child with thalassaemia than among those caring for a child with SCD. *Engulfment*, however, was usually temporary: most parents were able to rebuild their coping strategy and appropriate support could facilitate coping. Further, few if any parents confined themselves to a single, strategy showing some shifting of position. This characterizes most family carers' approach to their role (Twigg & Atkin 1994).

Service practitioners therefore need to consider the variable nature of the parent's coping ability and the vital part they can play in enhancing coping.

Parents' contact with services is known to be an important contributory factor to their ability to cope (Sloper & Turner 1992). Parents described how services could both hinder and support their caring abilities. Appropriate professional support can help reduce stress and facilitate coping by offering information, financial help, and emotional support. Unsympathetic responses from professionals, or their incompetence, however, meant many carers identified service provision as part of the problem, potentially undermining their ability to come to terms with the condition. Institutional racism often means that support to parents of children with a haemoglobinopathy is poorly resourced and inappropriate to their needs (Ahmad & Atkin 1996). This could be seen in terms of the perceived low priority of haemoglobinopathies in the health services, the unhelpful attitude of practitioners and the perception among some Asian parents that their consanguinity was blamed by professionals for their child's condition. Such responses added to the stresses associated with parents' role.

Focusing on the role of health and social care agencies in enabling parents to cope with their child's condition also reminds us that coping is more than an individual characteristic. A parents' difficulties in coping, for example, can be as much a reflection of inadequate service delivery and insufficient resources and racism, as a consequence of the condition. Service practitioners can also learn from parents' own coping strategies, and look to supplement them. Common coping strategies include the ability to achieve a balance between the consequences of the condition and the need to lead as 'normal' a life as possible, plus the occasional need to talk to someone about the demands of caring. Those families who are lacking in material and social resources, including a lack of supportive family are particularly vulnerable. On the service provision side, parents identify access to information about the condition and the support available to them as well as appropriate service delivery as fundamental in coping with a child with an SCD or thalassaemia. For Asian mothers access to specialist workers who had relevant cultural and linguistic background, was of great value and allowed them direct access to support which enhanced their coping ability. More generally, policy and practice, although needing to reflect parents' own resources and strengths in coping with their child's chronic illness, cannot abdicate its own role in helping parents come to terms with their children's disability or chronic illness and to provide them with optimal care without feeling engulfed.

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