

‘All her children are born that way’: gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya

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Objectives. To explore early experiences of sickle cell disorder (SCD) in families with a young affected child, and the way these experiences influence relations within families. To consider ways in which stigma could be counteracted in health and research programmes in sub Saharan Africa.

Design. A qualitative study was conducted in a rural area of coastal Kenya including in-depth interviews with 13 families affected by SCD and 12 staff of a local biomedical research programme. Purposive selection aimed to maximize diversity in socioeconomic and educational status, religion, severity of illness burden and religion amongst families and draw on relevant experience for staffs. Interviews were recorded, transcribed and analysed using the constant comparative method for family interviews and a thematic framework approach for staff data.

Results. Low initial recognition of SCD and its cause were associated with lay practices of surveillance within affected families, contributing to stigmatisation that occurred independently of genetic knowledge. Blame was often placed on mothers, including a risk of blame for misaligned paternity. Mothers are often particularly affected by SCD through the loss of independent livelihoods and their limited options in coping with this chronic condition.

Conclusions. Mothers of children with SCD were particularly vulnerable to stigmatisation within families, with underlying structural influences that suggest these findings may apply to other similar settings in Africa, and have relevance for other genetic conditions. The potential, nature and form of stigmatisation point to the role of effective communication and SCD management in addressing for blame and discriminative effects of having a child with SCD. The findings highlight the importance of broader social programmes targeting underlying gender and economic inequalities.

Keywords: sickle cell disorder; Africa; stigmatisation; gender; health policy

Background

Internationally, many social and ethical issues have been debated around genetic testing, both for the ‘new’ post-genomic era of genetics (Collins 1999, Hoedemaekers *et al.* 2006, Parker *et al.* 2009) that began with the initiation of the Human Genome

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Project (HGP) in 1990 and in the field prior to these developments (Markel 1992). Most guidelines and commentaries (Richards 1993, WHO 2002, National Council on Bioethics (NCOB) 2006) draw on developed country experience, with the notable exception from the report of the WHO (2006) on genetic services in developing countries (WHO 2006). Stigmatisation and discrimination in genetic testing emerge as important concerns across all eras and in all settings, at the level of the individual within a family, for the family within a wider community and for communities themselves (Phoenix *et al.* 1995). Much of the initial recognition of the risks of discrimination through genetic testing arose from experiences of sickle cell disorder (SCD) testing in programmes in the 1970s in the USA. Collectively, these programmes have been described as ‘a public policy disaster’ (Duster 2003) and as a Dickensian axiom of ‘How Not To Do It’ (Markel 1992).

As suggested by the references above, SCD itself provides an important example of the social and ethical issues in genetic testing, not least because the major burden of this disorder is experienced in malaria endemic countries in which, from a global perspective, there is relatively little health research conducted (Weatherall 2003) and where medical resources are often limited (Makani *et al.* 2007). In particular there are limited epidemiological and clinical data available from Africa on this relatively common and important condition (Makani *et al.* 2007). SCD in Africa is often a very severe condition with high mortality in young children due to anaemia and intercurrent infection, although there appears to be considerable variation in its severity. The mainstay of SCD management in developed countries includes early detection through neonatal screening, comprehensive care programmes and early detection and management of crises, with more recent therapeutic interventions of blood transfusion therapy and the use of hydroxyurea (Weatherall and Clegg 2001). Where these programmes are in place, adult survival has reached a mean of 48 years.

Greater understanding of the way in which stigmatisation can occur in genetic conditions, including testing, is important in developing strategies to counteract risks, including counselling, informed consent and disclosure processes. This has been emphasised in developed country settings by the introduction of SCD screening within public health programmes (Borry *et al.* 2007, Miller 2009). There is relatively little empirical data on experiences of living with genetic disorders or genetic testing from Africa. The WHO (2006) report on genetic services in developing countries illustrates this gap well; only four of its 278 referenced articles provide reports from this continent. Qualitative accounts have been published from developed countries (Rapp 1988, Featherstone *et al.* 2006), with specific attention to issues of discrimination (Atkin *et al.* 1998), but much of the data on experiences of genetic conditions from Africa (Bamisaie *et al.* 1974, Akenzua 1990, Ohaeri *et al.* 1995, Adeodu *et al.* 2000, Assimadi *et al.* 2000, Ohaeri and Shokunbi 2001, Ohaeri and Shokunbi 2002) draws on quantitative surveys and illustrates issues in limited geographic areas, particularly West Africa. Exceptions are qualitative accounts of SCD beliefs as reincarnation in Nigeria (Nzewi 2001) and Ghana (Allotey and Reidpath 2001), a description of biosocial illness associated with SCD carrier status in Senegal (Fullwiley 2006) and experiences of stigmatisation around the genetically influenced disorder podoconiosis in Ethiopia (Tekola *et al.* 2009). The prominence of SCD testing in these studies is expected given its public health prominence as a genetic disorder in Africa. This paper aims to contribute to understanding the nature, forms and conditions of stigmatisation related to genetic conditions within

families in Africa, by exploring the ground realities of SCD in a rural Kenyan setting. Key findings, including gendered aspects, are presented with some commentary before drawing on these findings and the literature to discuss the gendered nature of stigma, and the policy implications for communication and other aspects of health care and research, around SCD in this and other similar settings in Africa.

Methods

Study site

Participants were local residents of a rural relatively poor district in coastal Kenya, where the main livelihoods are subsistence farming and fishing. A more detailed description of sociocultural aspects of the community has been given elsewhere (Molyneux *et al.* 2002). The District General Hospital is the main site of the Kenya Medical Research Institute (KEMRI) Wellcome Trust research programme, a multidisciplinary international research programme focusing on health issues relevant to Kenya and other parts of sub-Saharan Africa. A series of studies on the health effects of the SCD gene (Williams *et al.* 2005) has led to the setting up of a specialised SCD clinic as collaboration between the research programme and the district hospital. One such on-going study includes a longitudinal cohort of children to investigate the relationships between human genetic factors and the risks of severe childhood illnesses, and includes predictive SCD screening of children in their first year of life.

Study participants

Families affected by SCD

Using SCD clinic records at the district hospital, demographic surveillance system data (Cowgill *et al.* 2006) and information from the genomics research, 13 families were purposively identified for inclusion in this study, aiming to identify diverse situations, in terms of representation of faith, mothers' educational backgrounds, rural or urban homes, use of SCD clinic and number of affected children (see Table 1). In 2009, 19 in-depth interviews were held with 13 families, with intervals of about one week between interviews where more than one discussion was held. Ten families had experienced diagnostic and three predictive SCD testing. Parents and other available members of the extended family were interviewed at home, drawing on narrative accounts of experiences with SCD over time, including perceptions of cause, practices, effects and patterns within the wider family. Interviews lasted between one and three hours and were conducted, recorded, translated and transcribed by a team including a first language Kigirima speaker as well as one of the authors.

Local residents working at KEMRI Wellcome Trust research programme

In 2009/10, 12 full time staff members from the research centre, who were also local residents, were interviewed individually or in small groups on community perceptions of SCD, its inheritance and impacts on family relations. Seven staff members were field workers with the genomics study, responsible for explaining the study and informed consent processes. Five staff members were community

Table 1. Summary of family characteristics.

ID	Child's age	Gender child F/M	Mother age (y)	Mother education (y)	Father age (y)	Father occupation	No. children affected	Religion ^a	Urban/rural (U/R)	Type of testing ^b
1	4y 9m	F	30	6	69	Teacher	2	C	U	D
2	3y 9m	F	22	7	29	Casual labourer	2	C	R	D
3	3y	M	28	12	45	Shopkeeper	1	C	R	D
4	5y 7m	M	40	0	50	Palm tapper	3 (2 died)	C	R	D
5	5y 6m	F	31	0	<i>N/A: single parent</i>		1	M	R	D
6	1y 2m	F	24	6	Not known	Bus fare collector	1	C	U	D
7	2y 10m	F	30	6	50	Plumber	1	C	U	D
8	2y 9m	M	30	12	30	Bus driver	1	N	U	D
9	1y 11m	M	30	0	43	Palm tapper	2	M	R	D
10	2y	M (twins)	25	0	Not known	Shopkeeper	2	M	U	D
11	2y 5m	F	30	0	Not known	Missing	2	C	R	P
12	1y 3m	F	39	0	39	Pastor	2	C	U	P
13	1y 8m	M	20	0	Not known	Stonemason	1	M	R	P

^aC, Christian; M, Muslim; T, traditional or other; N, none.^bD, diagnostic; P, predictive testing.

facilitators, undertaking community engagement activities across a range of studies, including the genomics study. Interviews lasted between one and two hours. Demographic data for this group of participants are given in Table 2. Interviews were conducted in English and documented as for the family interviews.

Analysis and interpretation

Analysis of data from approximately 28.5 hours of recordings of family narratives was based on the constant comparative method, using line by line coding, progressive categorisation and the development of analysis charts for comparison of emerging categories across participants. Analysis of perceptions of SCD inheritance and impacts on family relations also drew on data from the staff interviews, using a thematic framework method combining a deductive assessment within the themes generated by the family narratives, as well as an inductive search for new emerging issues relevant to these themes. Initial coding frameworks were independently developed by two researchers and analysis and interpretation discussed continuously within the team. Given the authors' background as staff within a research programme widely perceived within the community as providing medical support to the district general hospital (Molyneux *et al.* 2005), it was important throughout the study to recognise and take into account the potential effect of these roles on data collection and analysis. Positive descriptions of biomedical concepts and services have been particularly scrutinised, although in practice many participants expressed views that fundamentally contrast with biomedical paradigms and were at times deeply critical of the research programme. Data were managed with Nvivo 8 software to facilitate discussion and audit.

Scientific and ethical approval

Scientific and ethical approval for this study was given by the institutional review committee and national scientific and ethical review committees in Nairobi (KEMRI Scientific Coordinating Committee and National Ethical Review Committee).

Table 2. Summary of research centre staff members characteristics.

ID	Role	Interview no.	Gender	Age	Education (yrs)	Religion ^a
FW1	Field worker genomics study	1	M	34	12	M
FW2	Field worker genomics study	1	M	34	12	C
FW3	Field worker genomics study	2	M	27	12	C
FW4	Field worker genomics study	2	M	34	12	C
FW5	Field worker genomics study	3	M	30	12	M
FW6	Field worker genomics study	3	M	31	12	C
FW7	Field worker genomics study	3	M	33	12	C
CF1	Community facilitator	4	F	33	16 (graduate)	C
CF2	Community facilitator	5	F	43	12 + diploma	C
CF3	Community facilitator	5	M	35	12 + diploma	C
CF4	Community facilitator	5	M	37	12 + masters	C
CF5	Community facilitator	5	M	49	12 + diploma	M

^aC, Christian; M, Muslim.

Findings and discussion

Recognizing and managing SCD

In nearly all the affected families visited, there had been very low awareness of the term 'sickle cell disease' prior to their first child being tested for this disorder. This finding was typical of the wider community from staff perceptions of their experiences of communicating with families about KGBC and SCD over time. *Homa ya mifupa* is the Kiswahili term widely used for SCD in medical facilities in Kenya, or *ukongo ya misozani* in Kigiriyama, translating to 'fever or illness of bones'. In its early stages, families, including grandparents where they joined in the discussions, did not recognise the emerging intermittent signs of SCD as a specific disorder and gave no name to this collection of events. Over time, many children experienced very serious effects of the disorder, including severe pain due to crises, ill health associated with serious infections, frequent admissions to hospital, chronic tiredness, embarrassment and discomfort due to abdominal swelling and difficulty in maintaining normal social and school lives. The various symptoms were initially recognised and managed over time as disconnected entities with varying perceived causes and in different ways. Pragmatic combinations of biomedical and traditional health seeking practices were frequent; most commonly, a sequence of different actions was undertaken over time on a trial and error basis in an often highly anxious search for ways of relieving symptoms, particularly where symptoms were severe. Where contact was established with biomedical health facilities, a label of '*homa ya mifupa*' was given by health staff and generally used by the parents, whether continuing care was biomedical or traditional.

Looking for a cause

The same features that were linked with high levels of worry and distress in the family, namely the severity, unfamiliarity and intermittent but long term nature of the symptoms, also strongly influenced the family's overall responses. These included the strength of the need to find a remedy, but also to ascribe a cause. In this way, a family with a more severely affected child would, through their anxiety and distress, be more likely to try out many different remedies and to engage hard in identifying a cause.

For SCD in young children, the underlying causal mechanisms were either interpreted as natural, with explanations drawn from biomedical traditions, such as a form of malaria; or as supernatural, particularly ancestral curses (*laani*), spirits (*majini*) or devils (*shetani*). In this study, supernatural explanations were most common. This finding fits with staff perceptions that specific characteristics of SCD described above (severity, and lack of familiarity and cure) would be likely to generate suspicions of a supernatural cause in the community. Supernatural explanations for misfortune are common in many settings in Africa and elsewhere, and have been described in detail for a similar nearby Giriama community in the late 1970s and mid-1980s (Brantley 1979, Parkin 1991a, pp. 211–212). In this study, initial perceptions of the cause of SCD were in keeping with the general health beliefs of that family, but the lack of a cure for this genetic condition drove many families to move pragmatically between different types of health providers over time, and similarly to switch between different beliefs about cause over time. A mother's story

illustrated the co-existence of traditional and biomedical explanations. In the first interview in this family, she described (prompted by her husband, who had less formal schooling) a biologically accurate explanation for SCD inheritance, drawing on her 12 years of formal education. Later, in a second interview, she spoke strongly of her misgivings that the disorder had in fact resulted from an ancestral curse: 'According to my belief and what I am hearing, I think we can say it's like a curse from the lineage. It could be from the fore fathers or ancestors, I can't even explain what mistakes they could have made so that the curse follows these grandchildren' (M3).

In this genetic condition, a further important influence on family perceptions of cause was the existence, or memory, of another family member believed to be affected by the same condition. Given the non specific nature of many symptoms of SCD, this could include a confusing array of other health problems, including polio, cerebral palsy, malnutrition and forms of arthritis. Members of both the paternal and maternal clans would commonly scrutinise the extended family across several generations, with observations that could be interpreted as pointing to the source of the problem, including that one or both sides of the family were responsible. This practice of looking closely at family members over generations for signs of inheritance in genetic conditions, including a 'lay' tracking of features thought to be associated with familial conditions, is not unique to this community. For example, the same phenomenon has been described for genetic disorders in South Wales at UK, in which affected families described an intense process of scrutinizing current and earlier generations for clues on the origins and pathways for the disorder, termed 'surveillance' by the author (Featherstone *et al.* 2006, p. 73–91). Like this study community, their constructions of genetic risk were often related to lay beliefs, such as a perceived increased risk for a child who shared a hair colour with an affected relative.

Most commonly, where a linkage to an earlier generation was perceived, a suspicion of an ancestral curse was raised, as illustrated by the earlier quotation from the mother in Family 3. Less often, alternative supernatural explanations were considered as an explanation for the link between generations. For example, a young mother described a belief that devils can affect consecutive generations, whilst herself not fully accepting this explanation: 'It's like that, if I have asthma then my child also gets asthma or my brother's son gets it, I don't know how that passes from one person to the other. Because other people say there is asthma in clans and devils in clans, for example my grandparent might have the devils and then they come to me. I don't know maybe somebody who understood these things well from a long time ago can sit and explain it to you. . . now my child is breast feeding, how do the devils come from me to my child? You will forgive me, that question has defeated me' (M13).

Blaming within families

The Mijikenda community is described as a 'patrilineal' society by anthropological convention (Parkin 1991b, p. 84), or one where social and political identity and ancestry are constructed in the male line (Shaw 2006). In this rural setting, although cultural attitudes and practices are inevitably mixed and in a process of continuous change, marriage is traditionally arranged between families. This arrangement

involves the giving of a bride price by a man's family to his prospective wife's father, and is geared towards maintaining continuity of the paternal family line through the successful bringing up of children (Parkin 1991b, p. 84). Against this background, participants described a common general attitude in which mothers would often be seen by the wider family and community as having responsibility for the occurrence of any health problem in their children. In part this related to their practical day to day role in providing all aspects of care for their children, in which case ill health might be seen as a lapse of proper preventive, health promoting or curative care on their part. However, more fundamentally, many participants also described a tendency for mothers to be held responsible, and for fathers to resist accepting responsibility, for negative events in their children, where lapses in the mother's care were not identified or suspected. A field worker described that: 'I think...we men, you know, are...hard to take things, in fact, things which are on the negative side, I will try to pull myself out' (FW2). Similarly, a community facilitator explained: 'Let me be one of the fathers, us fathers, we normally if anything happens [to the child] in terms of diseases, we normally put a blame to mothers' (CF4). A more specific example of this phenomenon was given by a mother in discussing traditional beliefs about the role of mothers in causing problems in their children: 'In this community we say that the mother has bad spirits (*pepo mchafu*), those bad spirits are the ones that comes to attack the child until she suffers and will eventually pass away' (M9). Particular features of SCD were also related to this tendency by a community facilitator, saying: '...the community round here, when they find that a disease is rare you know they tend to blame it for, to be caused by the mother' (CF1). The likelihood of fathers being resistant to accepting their role in SCD was also described by most field workers and community facilitators, as shown by the following comments from a field worker in the genomics study during a group discussion:

FW7: ...most men from the community don't think they can, that their blood can be having this sickle cell disease, so they're always blame shifting, they always shift the blame to the woman.

Moderator: Are we just talking about sickle cell disease?

FW7: Sickle cell plus other diseases...he will always look for loopholes to blame, that is how the majority of men in the community behave.

A similar situation was reported by a field worker in discussing a couple's disagreement over the usefulness of parental testing: 'I know of a case where the wife wanted the husband to come and be tested [for SCD] but the husband refused...because he was telling the wife "you are the one who is causing my children to have sickle cell". So she told the husband he should go and be tested if you are not carrying the sickness or what. And the husband refused' (FW4).

Surveillance and blaming

Around this reported underlying 'cultural' tendency for maternal blame, an important additional and often cross cutting influence was the interpretation made by family members of observations, or surveillance, across the current and earlier generations. Such observations might point to more than one child of the same mother being affected, as well as family members on one or both sides of the

extended family. A strong implication of cause was often made for a mother who had more than one affected child, particularly where no previous generations were known to be affected. For example, the mother in Family 9 had two children diagnosed as having SCD at the district hospital, and at the time of interview the family suspected that the earlier death of an older child, treated by a traditional healer, had also been as a result of this disorder. The mother had recently given birth to a fourth child, too young to be tested for SCD. Her sister-in-law described her belief in the mother's responsibility for her children's condition several times, for example saying: 'The baby is still young but will come for the test too, because all her children are born that way, that one who is still young will then be in trouble'. A sister-in-law was also referred to as the source of blaming in this situation in Family 1, where a mother of two affected children explained that: 'He [her husband] doesn't say anything but his brother's wife says it's [SCD] from my family' (M1).

Regardless of whether one or more children in the current generation were affected, observations across earlier generations often strongly influenced interpretations of the origin of the disorder. At the same time, interpretations of these observations were very flexible, and therefore easily influenced by other beliefs or perceptions. The low recognition of SCD and consequent overlap between perceptions of this disorder and other conditions also contributed to the flexibility of interpretation. Most participants described that the perception of an absence of an affected family member on the fathers' side would greatly increase the risk of maternal blaming, independent of any observations made for the maternal clan. For example, a field worker explained: 'The men won't accept any blame to be put to their side, they will always blame the women...they will be blaming the wife that "you brought in the illness from your family because in my family I'm not seeing these conditions"' (FW9). In Family 9, this flexibility of interpretation supported denial of responsibility by the father, even though a paternal history of SCD was known. He argued for the negligible influence of the paternal clan through comparing the proximity of affected generations: 'You know in my father's generation and my generation sickle cell is not there but on my wife's side, it is there [in her generation]. . . so maybe our kids inherited it from her'. The strength of feeling behind his assertion was illustrated by his later making several forceful requests at the clinic to be tested for SCD, to show who was responsible for the children's condition.

In contrast, in Family 6, where surveillance led to a widely agreed perception that the paternal clan was responsible for the condition, this attribution of cause was not associated with blaming in the same way. The mother, whose two children were both affected and had experienced severe and frequent episodes of illness, did not express any blame towards her husband, but rather described her relief in his acceptance of the situation, saying: 'Since their father has accepted them, and also me I have accepted their condition, we are finding it very easy. If a child is sick, the father goes to work and by the evening he comes in bringing fruits, milk... so it's like he has accepted' (M6). In this family, it emerged that the mother's acceptance, and lack of blaming of the father's family, was strongly linked to her concern for the children and lack of options in providing care for them (see also the section 'Consequences of SCD for families'). Under these circumstances, the mother's reaction was one of acceptance, relief that the father had also accepted the children and gratitude for his support.

Questioning paternity

The findings presented so far suggest a potential risk that some mothers may be blamed for causing SCD in their children, and that this can occur either with or without a visible link to another affected person in the family, and also with or without having been given a biomedical explanation of its inherited nature. However, when inheritance forms part of the family's interpretation of the disorder, either from surveillance or from being given information about this, a further form of maternal blaming can arise from accusations of unfaithfulness. The risk of this perception was described in all interviews with staff, either spontaneously or when raised as a question by the interviewer. It was generally reported as a consequence of fathers' being unable or unwilling to accept a role in causing the disorder in their children, and therefore raising questions about the identity of the 'true' father of the child. As a field worker in the genomics study reported: 'So if the father does not accept that the blood line has that [SCD], definitely he will say "there is something to this. . . maybe you are moving out of wedlock"' (FW6). In addition to the tendency to resist blame for negative outcomes discussed in the previous sections, an important reason why the father might have difficulty in accepting his role is the invisibility of carrier status, and the challenges in understanding and accepting a 'healthy carrier' explanation as the mechanism for inheritance. Perversely, it seems likely that the greater the father's understanding that SCD must come from both parents, the greater chance that he will consider an explanation of misaligned paternity. A field worker described: 'So the moment you mention the two parents [as having passed on the disorder], the men will consider himself and his wife. "So if I don't have it, where did my wife get it?" That's where the fracas starts now. . . "who is the other parent who brought it to this family?"' (FW10). In contrast, three staff participants separately and spontaneously raised a distinction between explaining inheritance through the specific contributions of the parents as individuals, and as the more commonly understood phenomenon of the family lines. For example, a community facilitator pointed out the value of thinking about 'two types of inheritance in the Mijikenda context. . . those things you are born with by virtue of its existing in your family line, which is different from inheriting from your mother and father, as in it's so immediate. . . [talking about] that type of inheritance is very sensitive' (CF7).

Consequences of SCD for families

As can be understood from the preceding paragraphs, the impact of SCD on families included those related to taking care of an affected child and those related to the effect on relationships within the family. Both types of impact were accentuated where children were severely affected, including high levels of emotional distress as well economic costs of home care and treatment seeking. While the entire family would be affected by the costs of caring for a child with a chronic lifelong disability, economic losses particularly impacted on mothers, who were unable to establish or maintain income generating activities as a result of the high levels of childcare needed, and had relatively few options in coping with the disorder within their families.

A mother described her life at home with two affected children, saying: 'They will cry till you won't be able to do anything. . . I won't wash clothes and I won't be able to do anything, I will stay with the child the whole afternoon . . . the problem with them if they are sick is they don't want to sit, don't want to sleep but only want to be carried' (M6). Another mother talked of the limitations these types of worries placed on her life: 'When he has gone to school, like now, I don't ever leave the house and go far until he comes back home' (M3). The loss of income these restrictions entailed was described by a mother with affected twin boys saying: 'If the children are sick, will you leave them? . . . I was frying potatoes but when my children started getting sick then I stopped that' (M10). Those who were most secure financially were least affected by this challenge to an independent livelihood. A mother who ran a small busy general shop explained: 'When this [a SCD crisis] happens, I don't see this [finding someone else to run the shop] as important, I just close the shop. I haven't looked for anybody, even the time I was in the ward I closed it, till I was discharged is when I came to open the shop' (M8).

The situation in Family 6 was described previously (in the section on surveillance and blaming), with the paternal family strongly perceived as the main source of SCD in the two affected children. The mother's account of her relative powerlessness in the father's and her own family are illustrative of the lack of options facing mothers who take care of children with SCD. Her childcare responsibilities prevented her from seeking financial independence, her own family were reluctant to take her home with two chronically ill children, even for short periods, and she could not countenance leaving the children with her husband and a future substitute 'mother'. She explained: 'It's me and my husband who are to take care of our children but to tell the truth if I leave here and go to my home, the mother who will come [another wife] won't live well with my children. . . and if I decide to take my children to my home there won't be any one who will volunteer to take care of my children'.

Gendered forms of stigma in SCD

In this study, a potential for mothers of children affected by SCD to experience stigmatisation within the family was described in two main ways; for attribution of cause, where this was associated with blaming, and in the way that the disorder subsequently impacted on mothers' lives and choices. Similar observations of gendered blame for increased responsibility for genetic conditions have been made in other settings (Bamisaie *et al.* 1974, Naveed *et al.* 1992, Sharma *et al.* 1994).

Goffman's classical definition of stigma as 'an attribute that is significantly discrediting' (Goffman 1963) emphasises the role of characteristics of individuals and relationships with others in the process of stigmatisation. In this study, the physical signs and symptoms of SCD could be interpreted as 'discrediting attributes' and clearly led in some families to increased concern and pressure on relationships within the family. A father explained: 'To tell the truth, when we knew there was a problem, I even said "it's better I didn't marry you" because I felt very bad, and when things started to calm down then we sat and decided that we just leave this to God and He will know what to do' (F3). Importantly, there was no suggestion that children themselves were blamed or stigmatised for the condition, either by their own family members or the wider community, in contrast to some reports from West Africa on practices related to interpretations of SCD in young children as 'malign

reincarnation' (Nzewi 2001). However, it would be important to explore issues of direct stigmatisation for older children and adults with SCD, where the physical characteristics and social context are very different. Interviews with some parents and several staff members pointed to the risk of confusion between SCD and HIV/AIDS in adults, given similar features of chronicity, the need for regular medication and clinic attendance, an increased rate of illness and death, and low body weight. Continuing to follow an HIV/AIDS analogy, it is possible that increased uptake of testing and improved management for SCD would be an important part of reducing any such stigmatisation, given that the latter is closely related to the outward manifestations of the disorder, as has been shown for HIV/AIDS in Haiti (Castro and Farmer 2005). Similarly, in young children, reduction of the physical burden of the disorder through appropriate biomedical care would arguably reduce pressure on relationships within families, including risks of blame, amongst other more direct positive effects.

The stories of SCD in this study described a form of stigmatisation that moves beyond the individual/relationship concepts described by Goffman and towards recognizing structural influences in both blaming and discriminatory effects of having a child with SCD. Parker, in writing about HIV/AIDS stigma in developing countries, describes a structural concept of stigma as one that 'feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality' (Parker and Aggleton 2003). This concept takes account of social theories describing the work of power, culture and difference in producing and reproducing stigma and discrimination, where discrimination is defined as 'acts or omissions derived from stigma and directed towards the stigmatised' (UNAIDS 2005). In the field of HIV/AIDS research, the structural basis of gender discrimination for women in many developing countries is acknowledged, including that 'women are (already) economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. Being outside the structures of power and decision-making, they may be denied the opportunity to participate equally within the community and may be subject to punitive laws, norms and practices exercising control over their bodies and sexual relations' (UNAIDS 2000, p. 13).

The family narratives and staff interviews give a good illustration of structured influences in stigma that lay behind the blaming of mothers for SCD. The gendered nature of the blaming relates to a number of overlapping issues, including:

- (1) A common tendency for mothers to be blamed for problems in their children, linked to a patrilineal social structure;
- (2) Gendered interpretations of responsibility from lay surveillance within families of perceived related disorders, coupled with a low awareness of SCD itself;
- (3) Gendered risks of blame for misaligned paternity where inheritance is perceived, including through lay surveillance;
- (4) The limited options available to mothers of children with SCD to protect their own and their children's livelihoods, related to their roles in the family structure and the influence of poverty on mothers' resilience in meeting additional childcare costs and responsibilities.

However, in addition to gender, a marker for the importance of other structural features in this study was the superficially conflicting role of sisters-in-law in ascribing blame to mothers. This finding highlights the complexity of the notion of gender discrimination, and its cultural embeddedness. This study did not set out to explore the role of sisters-in-law in relations within families, and the number and range of families in the study limits more general discussion of this phenomenon. However, it is likely that, within a patrilineal society, women's power within the extended paternal clan is closely linked to that of their husbands or brothers. Blaming of mothers by their sisters-in-law for causing SCD could therefore represent gender discriminative practices of women against women, linked to the influence of a prevailing patriarchal power structure. Similarly, individual mothers' educational and economic status were described by staff as impacting on both the likelihood of maternal blame and the gender discriminative effects of SCD. An important element described was an ability to make financial contributions to the household, and this was linked to educational background. The fact that acceptance, rather than blame, was the main feature of the parents' relationships in the two families where mothers had the highest levels of education (Families 3 and 8) could be interpreted as illustrative of this point. The father in Family 3 explained, after finding family members with SCD on his wife's side were more closely related than his own: 'So we thought maybe from her, that's why it has come to us, but, okay, this is an illness, and even if I follow it up, where will I get the answer? The only important thing is to find treatment for it. That's where I ended'. Similarly the mother in Family 8, finding out there was SCD on both sides of the family, described: 'I was told there were people with this problem and. . .when I discovered this I didn't want to know more, I said let me just continue looking after my child'. No claim is made for an association between acceptance and education/economic status, as there are obvious alternative and additional explanations, including the role of individual personalities and relationships (Molyneux *et al.* 2002), as Goffman's concept of stigma underlines.

Emerging issues for policy

Counselling is widely acknowledged as a key component of managing genetic disorders in some parts of Africa (Akinyanju and Anionwu 1989), Asia (Naveed *et al.* 1992, Wang and Marsh 1992) and developed countries (Atkin *et al.* 1998). At the same time, there are obvious challenges in communicating about these complex health related concepts, particularly where there are underlying paradigmatic differences, resource limitations and emotional concerns. However, generating an understanding of the concept of 'healthy carrier status' and therefore acceptance of the role of *both* parents seems a particularly important area for communication, in order to address the risk of blame and stigmatisation of mothers. Although there is a potential concern that providing genetic information can generate or increase stigma (Tekola *et al.* 2009), the findings illustrate that 'blaming' within families often occurs *in the absence of any biomedical explanations*, based on lay understandings of inheritance and cause. Instead, it is arguable that generating more understanding of the origins of SCD, including the roles of parents and their wider families, can provide an important means of countering these negative attitudes, which largely stigmatise mothers. In the particular case of increased risk of blaming mothers for

misaligned paternity, these findings suggest that the exact way that information is given to parents is of great importance. In this setting, drawing on a concept of the influence of family lines may be less likely to provoke stigma within families than discussing the specific roles of individual parents, and therefore provide a useful way of initiating discussions about SCD in counselling. Given that the physical burden of SCD varies over time, the degree of stigmatisation within families may also change in a similar way and counselling should always be seen as an on-going and long term process. As part of this process, information on inheritance could be shared over time, taking into account the needs, understanding and circumstances of individual parents.

Recognition of the social basis for stigmatisation points to important ways of counteracting discrimination. For HIV/AIDS, strategies including advocacy, mobilising affected communities and social transformation through both judicial and policy interventions have been shown to be more successful than relying on individual counseling approaches and efforts to build community empathy (UNAIDS 2005). For SCD, beyond ensuring access to effective care and counselling, efforts to mobilise self-help and advocacy groups, address gender inequities and strengthen the rights of mothers may well have the same potential.

Conclusion

In this rural Kenyan community, where SCD often presents in early life as a mysterious and distressing disorder, blame is often attributed to mothers, particularly where more than one child is affected. Low recognition of the concept of healthy carriers influences interpretations of inheritance and may reinforce blaming patterns within families. Stigmatisation of mothers arises both through blaming for cause and through gender related differences in the impact of this chronic disorder, with potential sensitivities around paternity. Given similar structural influences, these findings on social and ethical issues associated with SCD may apply to other settings in Africa, and have relevance for other genetic conditions. As well as strengthening medical services and communication and counselling processes, the study highlights the importance of broader social programmes targeting underlying gender and economic inequalities.

Key messages

- (1) In this rural Kenyan community, where SCD often presents in early life as a mysterious and distressing disorder, blame is often attributed to mothers, particularly where more than one child is affected.
- (2) Low recognition of the concept of healthy carriers influences interpretations of inheritance and may reinforce blaming patterns within families.
- (3) Stigmatisation of mothers often arises both through blaming for cause and through gender-related differences in impact of this chronic disorder, with potential sensitivities around paternity.
- (4) As well as strengthening medical services and communication and counselling processes, health and research policy on SCD should support broader social programmes targeting underlying gender and economic inequalities.

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