



## 'I can die today, I can die tomorrow': lay perceptions of sickle cell disease in Kumasi, Ghana at a point of transition

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**Objective.** To describe the lay meanings of sickle cell disease (SCD) in the Ashanti region of Ghana.

**Design.** Depth interviews with 31 fathers of people with SCD; a focus group with health professionals associated with the newborn sickle cell screening programme, and a focus group with mothers of children with SCD.

**Results.** Whilst there are discourses that associate sickle cell with early or recurrent death, with supernatural undermining of family well-being, and with economic challenges in purchasing medical care, other discourses that value children and other family practices that resist stigma are also in evidence.

**Conclusion.** Lay perspectives on SCD are constructed in the contexts of enduring culture (the high value placed on children); changing culture (medicine and research as available alternative discourses to supernatural ones); altered material circumstances (newborn screening producing cohorts of children with SCD); changing political situations (insurance-based treatment); enhanced family resources (the experience of a cohort of young people with SCD). Above all the praxis of successfully caring for a child with SCD, and the political experience of sharing that praxis, stands in opposition to discourses of death and helps parents resist stigma and despair.

**Keywords:** sickle cell disease; chronic illness; genetics; lay perspectives; culture; newborn screening; stigma; Ghana

### Introduction

In this paper we consider sickle cell disease (SCD) in Ghana as an instance in understanding lay perspectives on chronic illness. Although there is a long history of considering lay perspectives, much of this focuses on North America and Europe. Moreover, any focus on lay perspectives in the developing world runs the risk of emphasising exotic notions of difference, constructing so-called 'primitive' lay views in opposition to 'advanced' medical knowledge of SCD. We begin with an overview of sickle cell in Ghana, a major chronic illness in West Africa, and the potential of newborn screening as a public health intervention. We then situate the issue of lay

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perspectives within the long tradition of writings in this area. This study reports on interviews with health professionals and the parents of children with SCD. It examines the lay meanings of SCD, the contextual factors that mediate such lay perspectives and the implications of such lay perspectives for policy development of SCD in Ghana.

### **SCD in Ghana**

Sickle cell disease is an inherited multi-system disorder that affects millions of people worldwide (Serjeant and Serjeant 2001). As many as 400,000 children with SCD may be born globally each year (Dennis-Antwi *et al.* 2008). Of these, over 80% are born in Africa, mainly in West and Central Africa (Modell and Darlison 2008). Measures from newborn screening of prevalence of SCD in African range from 1 in 33 in Nigeria (a probable over-estimate due to low numbers tested) to 1 in 57 in Burkina Faso and 1 in 71 in DR Congo. In the Kumasi newborn screening programme, 23.9% of infants tested carry a gene associated with SCD, and 1 in 55 of all babies born have SCD (Ohene-Frempong 2010).

Historically in Ghana, access to healthcare services depends on ability to pay. A 2003 National Health Insurance Scheme had enrolled two-thirds of the population by mid-2009 (Ghana Ministry of Health 2010) but the poorest remain outside the scheme. Newborn screening, coupled with penicillin prophylaxis, significantly reduces mortality and morbidity in infants with SCD (Gaston *et al.* 1986). Infections causing unnecessary deaths associated with SCD in developed countries are broadly the same infections affecting African children with SCD (Williams *et al.* 2009). This suggests that newborn screening would be an effective public health intervention in much of sub-Saharan Africa (Tshilo *et al.* 2009). At the time of data collection, the only organised newborn screening programmes in Ghana were in Accra and Kumasi. These began as pilot projects in 1995, and what historically in Nigeria, in the complete absence of treatment, had been estimated as an under-five SCD mortality rate of 98% (Fleming *et al.* 1979), and more recently in Kenya, where treatment for cerebral malaria was being implemented, as a mortality rate of 25% (Aidoo *et al.* 2002) became a mortality rate of only 5% for those enrolled into an SCD clinic (Dennis-Antwi *et al.* 2008). In 2010 Ghana commenced a national programme for SCD management with a focus on newborn screening, with sponsorship from the Ghana Health Insurance Scheme and the Brazilian Government.

In the absence of newborn screening, a diagnosis of SCD is often only made after several visits to hospital with acute illness, and most are presumed to live and die without the needed tests to establish correct diagnosis (Ohene-Frempong and Nkrumah 1994). There is limited public education on SCD and most information provided in an organised and consistent way in Ghana is from the centres in Accra and Kumasi. This provides an important context for understanding the nature of the lay perceptions about SCD.

### **Lay perspectives on illness**

There are several dimensions of the literature on lay perspectives on health and illness relevant to the experience of SCD in Ghana. First, for lay people, the perceived cause of disease may be important in orientating their social behaviour,

and is likely to be a product of their specific social and cultural circumstances (Blaxter 1983). Secondly, although sickle cell is inherited, the cause of illness may be variously held by lay people to lie with the patient, the natural world, the social world or the supernatural world (Helman 2000). Thus the social illness experience differs from the technical disease state in that it contains a moral dimension. Next, SCD is a chronic illness characterised by unpredictable painful episodes of variable length and severity. Accounts of lay perspectives on SCD in affluent societies note that young people and their carers negotiate their lives positively, actively engaging with social, cultural and material resources to address the challenges of the illness (Atkin and Ahmad 2001). Thus any accounts of Ghanaian perspectives need to take account of resistances (e.g., families *not* accepting folk wisdom about the genesis, likely life-span or probable experience of living with SCD) as well as challenges to living with SCD.

The interplay of ideas between authors of disability studies and medical sociologists also seems pertinent to our data. The social model of disability is a major resource in advancing the cause of disabled peoples in but loses sight of the corporeal body, particularly the body-in-pain (Williams 1999). SCD is a good illustration of the imperative to recognise the body-in-pain, since the pain is generally held to be excruciating and its episodic character psychologically challenging (Midence and Elander 1994). However, people with SCD, in the particular Ghanaian context we will describe, constitute bodies *who are there*. This is because the newborn screening programme produces bodies – literally bodies of people who would not exist were it not for the programme.

Fifth, people are not necessarily ignorant about medical issues, but rather medical knowledge is embedded within much deeper cultural beliefs about health and illness. In the US, Hill (1994) shows how medical messages about sickle cell are interpreted in the particular context of the inner-city poverty and racism. However, in the US and UK the rise in the awareness of sickle cell has been *alongside* the emergence of technical medical knowledge about the disease, whereas Africans have known of the manifestations of the disease for centuries (Konotey-Ahulu 1991).

Finally, there is the issue of the extent to which SCD in Africa is regarded as a spoiled identity (Goffman 1968). Where biomedical treatment and good nutrition are widely available, the latency of symptoms means someone with SCD has considerable potential for 'passing'. However, in a context of scarce biomedical treatment, somatic signs such as more frequent pain, yellow eyes, pot-belly, chronic leg ulcers and delayed growth, leave the person vulnerable to discovery. In Twi language, children with SCD are described as *Woayɛ ndwedwendwedwe*, meaning stunted in growth and likened to sugarcane in its knotted or segmented form. This is *not* to exoticise the account. Children with SCD burn more calories at rest, need greater calorie intake (Barden *et al.* 2000), and may thus be more somatically identifiable in a country with a per capita income of only 5% of the US or UK.

The US and UK literature presents extensive information about lay perspectives on selected chronic illnesses, yet a disease of such epidemiological importance in Africa such as SCD has been relatively uncharted. This article aims to contribute to the literature on lay perspectives to chronic illness with particular reference to SCD in the Ashanti region of Ghana.

## Methods

The study was carried out between 2004 and 2006 among fathers and mothers of children with SCD and a group of specialist health workers at the Kumasi sickle cell clinic. The lead researcher worked as the health communication specialist for the first 10 years of the pilot newborn screening programme and was therefore known to the health workers and the patients' support group. The main methods of data collection we used were two focus groups (with nine mothers of children with SCD and with seven health workers respectively), which helped guide questions for in-depth interviews with 31 fathers of children with SCD. The methods were selected as a means towards generating detailed empathic understanding of human action (Bryman 2001) with reference to the topic at hand: lay interpretations of SCD.

Ethics permission was obtained from UK and Ghanaian university ethics committees and the Sickle Cell Disease Association of Ghana. Informed consent entailed the preparation of an information sheet, read to potential participants in the local language of Twi (spoken by the first author). In order to address variable levels of literacy among respondents consent to participate was verbal, and was taped at both the beginning and end of the interviews. Participants were accessed through the social support group in Kumasi. We used open-ended, semi-structured questions.

Mothers and health workers were recruited through volunteers from the local support group and local clinic respectively. Seven fathers were recruited through self nomination at the support groups. Attendance at a total of three support group meetings produced a further 36 fathers of SCD children nominated as potential respondents by the mothers. Of these 36, two were not contactable; four were not accessible (e.g., working abroad); 23 were contacted and interviewed. The final seven were not interviewed as it was felt data saturation had been reached. These seven were offered, and two took up, an opportunity to meet the researcher for an update on care of their SCD child. Finally, in searching for disconfirming evidence (Glaser and Strauss 1967), we sought interviews with fathers not supporting the child with SCD financially or in kind. Contrary to popular impressions given at the support group, only 11 fathers of 256 support group members were no longer married and of these 11, only three were reported to have 'absconded' providing no support. One of these three agreed to be interviewed. This father became the 31st interviewee.

All verbal communications were tape-recorded and labelled using a predetermined identifier such as Father 1 (F1), Mother 2 (M2) or Health Worker (not enumerated to preserve confidentiality). Tapes and transcripts were stored securely in locked premises or password-protected computers. Full translation and transcription of the interviews were carried out in English by the lead researcher. Analysis of the transcribed data was by thematic analysis.

Characteristics of the fathers are given in Table 1. The age of the mothers was between 23 and 52 years. Three mothers were traders, four were unemployed (formerly traders but suspended in order to care for SCD child), and there was one seamstress and one nursing assistant.

The credibility of data obtained through semi-structured interviews depends on providing respondents with the opportunity to present themselves within their own frame of reference, and on the researcher's reflexivity of the impact of their social identity on data generated (Bryman 2001). Since the lead author had been known to respondents as a government health official, her understanding of SCD would have

Table 1. Characteristics of the sample of fathers of children with SCD.

Father	Age	Occupation	Religion	Relation to mother	Total children	SCD children	SCD children died
F1	34	Clerical officer	Christian (Methodist)	Married	2	1	1
F2	42	Low-income farmer	Christian (Pentecostal)	Married	3	1	1
F3	29	Bar-tender/student	Christian (Presbyterian)	Unmarried	1	1	0
F4	50	Low-income minister	Christian (Apostolic)	Married	5	2	0
F5	52	Teacher	Christian (Catholic)	Married	4	1	1
F6	48	Low-income farmer	Christian (Pentecostal)	Married	4	1	0
F7	54	Middle-income civil servant	Christian (Methodist)	Married	4	2	1
F8	41	Middle-income trader	Christian (Catholic)	Married	3	1	0
F9	49	Timber merchant	Christian (Pentecostal)	Married	4	1	0
F10	43	Carpenter	Christian (Adventist)	Married	4	1	0
F11	37	Sales assistant, shoe shop	Moslem	Married	2	1	0
F12	49	Cab Driver	Christian (Pentecostal)	Married ( $\times 2$ ) Cohabited ( $\times 1$ )	4	2	1
F13	43	Vegetable farmer	Christian (Presbyterian)	Married	5	1	0
F14	50	Cocoa farmer	Christian (Methodist)	Married ( $\times 2$ )	3	1	0
F15	44	Self-employed brick maker	Christian (Deeper Life)	Married	4	2	0
F16	37	Banker	Christian (Catholic)	Unmarried Married	1 2	1 0	0 0
F17	56	Teacher	Christian (Catholic)	Married	4	1	0
F18	36	Senior clerk, public company	Christian (Presbyterian)	Mother died Married	1 1	0 1	0 0
F19	44	Minister	Christian (Presbyterian)	Married	2	1	0
F20	41	Senior farm stockman	Christian (Catholic)	Married Married	4 2	1 0	0 0
F21	65	Photographer	Christian (Catholic)	Married	5	3	2

Table 1 (*Continued*)

Father	Age	Occupation	Religion	Relation to mother	Total children	SCD children	SCD children died
F22	70	Building contractor	Christian (Catholic)	Married ( $\times 4$ )	16	3	2
F23	49	Driver	Christian (Methodist)	Married	4	1	0
F24	35	Mason	Christian (Catholic)	Married	2	0	0
F25	38	Food-crop farmer	Christian (Pentecostal)	Married	2	2	1
F26	28	Primary teacher	Christian (Catholic)	Unmarried	4	1	0
F27	31	Petty trader	Christian	Married	1	1	0
F28	41	Accountant at bank	Christian (Adventist)	Married	2	1	0
F29	40	Laboratory technician	Christian (Presbyterian)	Married	1	1	0
F30	48	Teacher	Christian (Methodist)	Married	3	1	0
F31	40	Cash-crop farmer	Christian	Married	2	2	0
				Married	0	0	0

Note: We do not have complete information to assign particular numbers of children to particular relationships for F12, F14 and F22.

been considered high status. To minimise this social distance, interviews were conducted in Twi (not English as the language of officialdom) and she reciprocated at the end of the session by answering questions asked about technical medical information. Reliability in qualitative research is generally taken to refer to the replicability of the process rather than the findings, and this section comprises the attempt to be transparent about processes undertaken. The sampling strategy meant that those who were less integrated into the local support group were less likely to be recruited for interview, and this may under-represent less affluent families and/or those located in more remote rural communities. The generalizability of findings is further limited to the extent that parents accessed through the newborn screening project had exposure to positive messages from the support group and health workers about SCD and may be atypical of others areas of Ghana or sub-Saharan Africa without screening. However, as Plummer (2001) argues, small numbers can serve to demonstrate what is *possible* and therefore, in principle, transferable, were newborn screening and health education for SCD to be introduced across Africa.

### Findings: lay discourses on SCD in Ghana

When making sense of chronic illness, people generate their own biographical account within the framework of their broader social and cultural context. This results in multiple discourses operating. We identified seven main themes within two broader discourses. The themes are broadly discourses of death, including

(1) SCD as a 'bought disease'; (2) SCD as strongly associated with early death; (3) SCD and recurrent death and (4) the costs of SCD treatment as a source of financial pressure. They also include discourses of life including (5) pronatalism; (6) resisting stigma and despair and (7) utilising ongoing practical experiences and professional advice. We address each of these themes in turn.

***SCD: a 'bought' disease ('Nto yare')***

Fathers and mothers of SCD children may be faced with folk explanations behind their child's SCD. A typical explanation is the belief that SCD is a 'bought disease which your enemy purchases to afflict you or your family to bring hardships onto you' (F17), where spirit mediums purchase the disease and inflict it upon the family through the birth of the child. One father encapsulated these ideas:

Those with big abdomen are said to have a demonic pot in their belly. Those with chronic ulcers are considered as witches and wizards and that they use their legs as chopping boards for chopping the human meat they spiritually acquire (F5).

However, in all cases such references are to the beliefs and attitudes of *others*, not the mothers or fathers themselves. The beliefs are 'commonly perceived' (M5), 'said to' (F5), 'I have been told' (M1) or 'they sometimes say' (F4). It would be easy to exoticise these accounts, but such distance in referencing is important because it suggests a logical gap between discourses circulating in wider society and conceptions of SCD of parents themselves:

They perceive it as a 'bought disease – Nto yare'. [...] Most often, society does not put a blame on the parents of the child but rather sees it as due to an external source – witchcraft, spiritual disease etc. But I was not very much worried about that because in times past I believe they were not able to identify the disease and not much research had been done on it (F3).

In the context of the research-funded newborn screening programme in Kumasi and associated health education of parents, this father indicates he has been able to draw upon a medical model of SCD, underpinned by research, to characterise supernatural conceptions of SCD as knowledge whose currency is waning.

***SCD and early death – I can die today, I can die tomorrow ('Ene mewu: Okyena me wu')***

Lay observation of people categorised as having the 'bought' disease suggests that such children are often ill, look sickly and do not live long. Parents are uncertain as to when the 'death' is going to occur and persuade themselves that the child is passing through life only briefly. Lay descriptions include '*onye kye ba*' (he does not look like one who would live) or '*Ene mewu: Okyena me wu*' (I can die today, I can die tomorrow). Again, we note that in such cases, mothers and fathers were recounting the views of others at second hand: 'they also say' (F4); 'I had heard that' (M5) or (below) 'they perceive'.

It is because they perceive that as a parent, if you have such a child, you should not count him amongst your children. He is to live only for a brief period. He could die at any time so it is not worth it relying on him (F6).

Parents are encouraged to discount such children as socially dead (Sweeting and Gilhooly 1997), as non-existent in social terms, and to wait patiently for the day of their biological death.

But previously during the life of my first son, I was greatly influenced. So even in his time of ill health, I often did not pay much attention to him because I was convinced he would die anyway. I was told that such children ultimately do not go beyond 25 years of age (F5).

In this example, the father acknowledges that he was influenced by the death discourse for his first SCD child (now dead, possibly with a self-fulfilling element) but implies a changed outlook for his subsequent SCD child. In another interview with a father, he narrated a case in which a particular child other than his own had been neglected by the parents.

I have had people tell me that there is no point in investing in such a child because no matter what you do such a child would ultimately die. I know of a woman who has such a child and has virtually neglected her because she believed in what people say that the child would die. It was even my partner who informed me that that child has SCD. So sometimes I give that child some of my son's medication. I have even informed my partner that if it is possible she should take that child along to the clinic on her appointment dates (F3).

What is noteworthy about these comments is that they contain considerable resistances. In the latter quotation the father has assumed a role of community expert in which he recognises the existence of a death discourse. However, not only does he reject this framework for his own son, but reportedly shares his son's medicine with the other person's SCD child and asks his wife to take that child as well as his own to clinic. Learning through one's own practical experience and sharing that experience with others suggest mechanisms through which lay culture is transformed.

### ***SCD and finance: money will finish ('Sika be sa')***

Direct payment for health care was mentioned by all our respondents as a key factor underlying some of the lay perceptions of SCD. Calling a child with SCD 'money will finish' reflects the belief that the enemy uses the illness to drain the family finances. Parents spoke of restrictions on travel abroad to improve prospects (M8); working to save for costs of care for the child with SCD (F2); crying because they could not afford the necessary drugs for treatment (M9); and selling personal belongings to break even (F4).

However, the vivid descriptions parents gave of the financial aspects of their childcare are socially and historically contingent: newborn screening that reduces morbidity of SCD, insurance-based access to treatment or generally improved socio-economic circumstances could all improve the health of children with SCD and reduce economic pressures on the family.



***SCD: the cause of recurrent death ('awo m'awuo')***

Nzewi's (2001) study of the Igbos of Nigeria describes *malevolent ogbanje*: chronically-ill children who are born and die repeatedly in a process of reincarnation constituting supernatural revenge against the family. As with Nzewi's study, parents here reported hearing families give dirty or death-related names to children born after recurrent death experiences, in a bid to culturally resist the disease. Such names included 'sumina' (meaning garbage); 'sei ntoma' (you waste cloth); 'begyina' (stay live or don't die); 'te na baabi' (stay somewhere); 'yadee eye ya' (suffering from a chronic illness is a painful experience); 'ababio' (you have come again). The health workers recounted that the newborn child is given an identification mark on key parts of the body (face, shoulders, wrist, ankles or feet), referred to as 'Donkor', meaning one with facial scarifications, so that if the child dies, it cannot come back as it will be recognised immediately with the identification mark. However, where one father (F4) refers to reincarnation, he does so with scepticism, 'if you believe in reincarnation', implying that he himself does not. Even where a father has personal experience of scarification associated with beliefs of reincarnation, he distances his current world view from this past experience:

As for the scarification, it is true. I have seen some. When I was a child I remember I became severely ill, was admitted at hospital but I did not improve. The doctor therefore discharged me and my mother took me to a medicine man. He made scarification on my body (you can even see it) and gave my mother herbs to use in bathing me. Hmm! For those of us in the villages, we have had so much suffering due to the disease. Our parents have relied so much on such medicine men and herbs to care for us. It is just recently that we have been saved through this newborn screening programme (F6).

Whilst the final phrase may be for the benefit of the high status health professional interviewing him, it is also possible that the personal experience of scarification (40 years previously in a rural area without service development) is being contrasted to the changed world that a newborn screening programme and access to services represents. This is because, for the father, newborn screening offers both an alternative cause (a medical diagnosis) and preventive and treatment methods that render early death, and hence the reason for scarification, considerably less likely.

Thus far we have located the parental experience of SCD in relation to discourses of death: sickle cell as a disease supernaturally implanted into the family, entailing early and recurrent deaths and undermining the family budget. However, as we have seen, this does not mean parents passively adopt these world views, nor does it mean that their orientation to them remains the same over time.

***Situating children: a 'must have'***

Having children is important to the African irrespective of age, educational level or occupation because it proves ones fertility, marks an adult status and creates ties of obligation (Richards 2002). All fathers referred to the cultural imperative to have children, or that remaining childless once married was not an acceptable situation within Ghanaian society.

Eeh! As for children I must have. Children are important to me. The way things are going on in this world if a man lives with a woman, they must have children. In our culture, without a child, a marriage is said not to be stable. The family would usually advise you to marry another woman or have a child elsewhere. It is only the whites who are able to agree that because of something, say disease, they will not have children. But not here in our culture (F8).

Respondents suggested that pregnancy has a place in a taken-for-granted temporal order in relation to marriage and other family members who have children. Respondent F8 is presumably looking primarily to the UK and the USA for the comparison that voluntary childlessness is a prerogative of 'whites'.

The strongly pronatalist context is reflected in the views of mothers too, who would rather have a child with SCD than not to have children at all. Their accounts suggest that concerns that a child with SCD disrupts the parental narrative of their child's life are overridden if that narrative can be positively reframed as retaining potential for educational success (M7); if their vulnerability can be managed by the father channelling all his inheritance to the one child with SCD (M6) or where care of an SCD child is framed as 'having no option' and stoic carrying on can be reconciled as not amenable to choice (M5).

### ***SCD: resisting stigma***

Stigma, in the original formulation of Goffman (1968), was about relationships not attributes, though as with many sociological concepts that pass into everyday usage, it is sometimes misused as the latter, not least by health workers:

In the Ghanaian society any ailment which is associated with high level of morbidity, mortality and chronicity is *automatically* stigmatised (HW; our emphasis).

However, as stated, stigma is a relationship, and for sickle cell to be stigmatised requires us to understand the social structures against which sickle cell represents an alleged discrepancy.

With a high risk of death and the changes in physical appearance, SCD allows for societal gossip (criticism and negative comments) often leading to the loss of reference to the mother of the child by her real name but rather by the physical appearance or course of the child's disease. E.g., 'Don't you know the woman with the big headed child with yellow eyes and lanky physical appearance?' or 'Do you know the woman who has been having frequent child death?' When she has a baby, the child dies in the first five years of life (HW).

Thus reported expectations of Ghanaian society include assumptions of a 'normalised' body; that children will survive parents; that children represent an economic investment not a financial drain; and that illness is acute and ameliorable not lifelong and intractable. One health worker recounts an episode presumed illustrative of the genesis of stigma: that others do not play with the child with SCD because he is perceived as weak and infectious. The worker also claims this leads the parents 'to deny SCD and keep it a secret'. However, whilst the newborn screening programme is being introduced, we must also consider that the health workers themselves are in transition in creating new specialist roles. In terms of their formation of professional

identities, their discursive practices emphasise a distance between the 'traditional' lay views (stigmatising, denying SCD, hiding SCD away as a secret from wider society, and resorting to faith over science) and their professional discourse.

Thus health workers recounted that among parents of SCD children, it was a common occurrence not to disclose that their child had SCD. Even in circumstances when they had received medical evidence of the presence of SCD in their newborns, they reportedly denied the diagnosis and refused to report to hospital until the child showed signs of serious illness. The health workers attributed this to the wider discourses of deaths discussed above. However, a closer examination of the accounts of the parents suggests otherwise.

I did not tell anybody because I was afraid that somebody may use that opportunity to worsen the illness and if possible kill my child spiritually (M8).

The mother apparently refers to not telling anyone, but this can only be in the short-term, because her presence in the focus group telling eight other non-relatives that she has a child with SCD contradicts any interpretation of non-disclosure as ongoing. Whilst initial reactions upon diagnosis may entail a stated intention not to disclose (which in terms of actual actions may or may not be consistently held to even in the short term), the majority of fathers and mothers did, in the contexts of finding practical ways of being in the world with their child with SCD.

But you see you need to study your environment and know what to share with whom. For instance in the house where we live, we tell people so that in case we are not around our child could receive better attention. But at work for instance you would not share this carelessly because of wrong perceptions and discouraging statements. When he was diagnosed, my parents and that of my wife were informed. My friends were also told including my friends in the health sector. His school is also aware (F18).

In the light of the prevailing discourses of death, parents may have been circumspect and selective about whom to disclose or discuss the news of their child's condition, but they did not appear to act as perhaps first intimated to the health workers. Selection of such confidantes depended upon the perceived value of the person as a source of support. Respondents informed their best friends. They informed their parents or in-laws to ensure appropriate childcare should they have to become care givers. The siblings of parents may also be informed in order that such siblings exempt them from familial financial responsibilities in view of their having to save up to meet the cost of care. They would also be informed because of regular association of their families with each other as they visit. Some health workers also build a social bond with the parents that qualify them to be counted as 'family'. Although intention-to-secrecy may be an initial reaction upon diagnosis, most parents actually developed the opposite approach of strategically sharing their child's SCD with significant others.

### ***SCD: resisting despair***

In the focus group one health worker summed up two types of parental reactions to being informed the child had SCD:

I think parental reaction to SCD is very much dependent on whether or not the person has a previous experience with SCD. If they have, telling them of the child's diagnosis is like announcing the death of a loved and close relative. They become desperate and throw their hands up in despair. There have been several instances of people weeping and crying in this clinic during our education sessions for first visits. For those who do not have any experience, there is minimal reaction from them until they experience the challenges of the disease (HW).

Parents expressed variable responses reflecting their attempt at coping with the news of their child having SCD. Some of these did indeed reflect the health worker's experiences that the moment of realisation was a moment of extreme emotional suffering. However, contrary to the initial reaction that SCD children had no foreseeable future, the responses suggest not only a resistance to despair, but might be conceived as both reflecting and constituting a change in the place of SCD in the culture of Ghana. The strategies ranged from investing in the positive framing 'that SCD patient can live up to even 60 years so the news did not put me down' (M5); drawing on existing family knowledge and associations with health institutions (M6); initiating participation in usual social activities such as attending school (M7); voluntarily restricting overall family size to channel resources to the child with SCD (F4) and harnessing available resources towards saving as a form of social insurance for the SCD child should they as parents die (M6, F4 and F5).

As in other contexts with African-American respondents (Hill 1994) religion as a form of responding to the challenges of chronic illness was a strong theme in the accounts of parents in Kumasi.

I also believe in God. He has been my source of sustenance.[. . .]. I sell eggs and there have been instances when God has miraculously supplied me with the finances to meet cost of care. My eggs sell very at a faster rate. Sometimes, when I don't have money, the farmers are prepared to let me buy some eggs on credit (M7).

However, as Atkin *et al.* (2008) have commented, using religion as a source of support does not imply fatalism, nor does it index any reduction in active engagement with the challenges on living with SCD. Although the mother refers to God, this is in the context of her active engagement with economic trading activity to provide a life for herself and her child with SCD.

### ***SCD children: learning through experience***

Fathers reported generating a good deal of knowledge through observing the children with SCD and experiencing care-giving in times of illness. Fathers portrayed themselves in varying degrees as 'lay experts' in home maintenance of SCD, knowing what to do when the child had fever, what foods to give, what medications to give, appropriate clothing in which to dress the child, managing pain, which outdoor games they could allow the children to get involved in and when to go to the hospital. Over the period of their children's life with SCD, they had been able to incorporate medical knowledge of SCD in their lay construction of SCD in order to determine what they thought worked for them. A majority (21) of the fathers stated that they acquired such knowledge through family interactions and care-giving negotiations between their wives and themselves in their daily lives.

They don't thrive on cold foods, cold weather, walking about naked. I am very particular about his food and how he plays. I ensure that he takes his daily medications (F10).

He has two main symptoms. When they appear and persist for about 3–4 days you know he is getting sick. One is cough. The second is pain. So every night I try to massage that part that he complains of before he goes off to bed. But the major is cough. When he starts, we get him some cough syrup and when it does not improve we immediately send him to the clinic. Sometimes the massaging request is a strategy he uses to get to sleep (F12).

Furthermore, 14 fathers made what could be interpreted as positive framing remarks about their children with SCD and their future. They referred to young people with SCD existing not dying, attaining adulthood, obtaining gainful employment and achieving a high status occupation (medical doctor), and appeared to find such conceptions enabling. Though the medical model of SCD management has been criticised in other contexts for not presenting a coherent strategy (Hill 1994), the parental information attendant upon the particular model of social medicine at work through the newborn screening and health education pilot programme in Kumasi is reportedly of immense benefit to parents. Parents also stated that joining the patient and parent support group had had a positive impact on their attitude to SCD.

## Discussion

The accounts of the fathers, mothers and health workers suggest that people living with SCD in Ghana and their carers are faced with considerable challenges. At first glance, there are myriad accounts of supernatural revenge, death and reincarnation and the undermining of family coherence through monetary costs associated with bringing up a child with SCD in a lower income country. Whilst not denying the cultural and economic context facilitates social relations that stigmatise the child and its family, we must avoid what Silverman (2006) refers to as accentuating the exotic in accounts, especially in this instance of lay accounts of illness in a developing country. Certainly, there are a number of 'discourses of death': but these potentially *undermine* the lives of children with SCD as much as describe them. Furthermore, culture is not monolithic, nor it is unchanging, nor still is it unchangeable. First, many of the negative discourses are *reported* accounts, sometimes even third hand accounts, and as such are more akin to morality tales than to contemporary descriptions of actual experiences. Secondly, a number of the fathers are relatively older men and their accounts in some instance refer back in time, leading one to question both the contemporary and future currency of such discourses. Thirdly, there is an element of co-production in eliciting this information: the lead author was encouraged by co-authors to find a means of evidencing her own contextual knowledge of these discourses, and this was achieved by asking the health worker's focus group to recount what they knew of such phenomena.

Finally, but perhaps most importantly, the fathers recount many ways in which they effectively mount challenges to such discourses. They draw on the alternative prevailing cultural discourse that regards children as a 'must have', and find strength: a child with SCD can achieve and attend university, what little wealth can be channelled to the young person with SCD because siblings have the strength to care

for themselves, and simply ‘carrying on’ with care can itself create a sense of purpose. Certainly too there is despair. But accounts of health workers tend to be accounts of the moment of breaking of the diagnosis, and accounts of parents at the moment they realise the implications of having a child with SCD. Despair is in that moment (and the moment may be revisited at points of crisis) but it is not a constant, fixed, unchanging correlation of having a child with SCD. The carers are at other times extremely resilient and resourceful finding ways to manage the demanding financial costs they face. Moreover, in being bodies of young people who survive (because of newborn screening), they are there for parents to interact with, and in this interaction the parents learn ways of being with and caring for their child with SCD, ways that, even if just for a few years, negate the discourses of death. If the child becomes a young person at school, or a young adult with an occupation or a family, then they are, in their very being, counterfactual to the discourses of death. Furthermore, in learning health education messages (a low cost key element of a newborn screening programme) about recognising signs and symptoms of SCD, undertaking preventive and precautionary measures to reduce episodes of SCD illness and in paying for medical treatment: all these too constitute ways of being in the world with a young person with SCD that helps to resist relationships of stigma and despair with the wider society.

There are a number of policy conclusions that may be drawn from these accounts. First, just as parental health education and newborn screening go together, so wider community education that challenges stigma cannot be initiated as an isolated policy. It would be unethical to create a theodicy of SCD infant survival in the absence of newborn screening, parental health education and widening access to health insurance. Such community education would not work in the context where lack of screening, health education and treatment are associated not only with enduring high levels of SCD infant morbidity and mortality, but where such SCD is undiagnosed and where therefore particular premature deaths cannot definitively be attributed to SCD. Secondly, in the transitional periods where newborn screening is recently introduced, (for example other, more rural, areas of Ghana outside Accra and Kumasi) health professionals have a special duty of care not to alienate local populations by unthinking dismissal of lay perspectives of SCD deaths. Health workers must be careful not to disparage supernatural beliefs nor lay strategies for coping with SCD symptoms (such as, in the absence of drugs, tying up with ropes to reduce SCD pain), since such beliefs ‘make sense’ in contexts where premature deaths and lack of treatment options prevail. Such community relations are needed for that transitional time when newborn screening does reduce premature deaths and when insurance coverage does increase treatment options. Thirdly, our research suggests that in transition to newborn screening, certain social relationships are enabling, and using a small but significant proportion of overall funds to strengthen such relationships would help the overall programme. Such relationships worth bolstering include initial parental health education and the opportunities for social support through formation of voluntary groups. The latter could disburse small funds to support the dissemination of the lessons of mutual assistance between SCD families and the lessons of mutual demonstration of positive ways of being with children with SCD between families. Last, young (and eventually not-so-young) people living with SCD themselves serve as living exemplars of people with SCD in education, in employment, and as parents and carers. Health professionals and community

development workers need to work with such SCD achievers in careful ways, co-opting key social interests such as church leaders, the media and politicians to positive framing messages of SCD, so that people with SCD are themselves not left unsupported when they make themselves vulnerable in standing up publicly for SCD interests.

### **Conclusion**

This paper has considered a particular instance of lay perspectives and chronic illness: the case of SCD in Kumasi, Ghana. The research elicited the perspectives of fathers of children with SCD through depth interviews, supplemented by a focus group with mothers and another with SCD health workers. Lay perspectives are not homogenous, hypostatised cultures which stand in opposition to a medical model of SCD. The discourses of early, recurrent deaths with supernatural forces and the economic undermining of families are not essential attributes of lay cultures on sickle cell in Africa. They are formed in the specific historical circumstances of an illness known for centuries before Western medicine defined sickle cell, formed in economic circumstances in which relative poverty and lack of biomedical treatment marks bodies out as 'different' (skinny, pot-bellied, yellow eyes, recurrent leg ulcers); formed either in the absence of newborn screening, or, in Kumasi, in the presence of such screening that drastically reduces deaths, provides health education strategies and provides treatment. It is formed in the wider cultural context of the social valuing of all children. Methodologically, in considering accounts of culture we need to factor in how these accounts are (co)-produced and the currency of such accounts. In considering parental reactions to a child with SCD we need to distinguish between moments in time, such as the occasion a diagnosis is communicated, and everyday long-term lived practices and not reduce the latter to the former. Nor is stigma an automatic concomitant of SCD in Africa: relations of stigma exist and flourish in particular social circumstances but conversely, resistances to stigmatisation exist and could be strengthened. The most important counterpoint is the very existence of a sizeable cohort of young people with SCD in Kumasi where previously (and elsewhere in Africa) there were but few individuals. The Ghanaian Government is scaling up the Kumasi programme to cover all of Ghana, but there is currently no policy on evaluating the lives of the new cohorts of young people living with SCD through social research. This would be important in order to ensure that opportunities for their education and employment are maximised, through, for example, effective policies for preventive health and educational support in schools.

The lay perspectives portrayed here do not represent Ashanti culture. Nor can such lay perspectives be construed as exotic difference from technical medical knowledge. Rather these perspectives are views in transition because of newborn screening and the resistances that the new bodies of people with SCD and their families can bring to bear on discriminatory attitudes. They are therefore lay perspectives of SCD at a key point in the transformation of Ghanaian health services, and perhaps, if newborn sickle cell screening becomes widespread, the transformation of the whole of sub-Saharan Africa.

### Key messages

- (1) Most literature on lay perspectives originates in the USA or UK, but we know less about the major chronic illness affecting millions of Africans, SCD.
- (2) Discourses of death around SCD, representing early, recurrent deaths under the influence of malevolent supernatural forces are referred to rather than accepted by parents of children with SCD.
- (3) Health workers may mistake transient expressions of despair, denial and felt stigma at time of first diagnosis for the longer-term resistances of parents.
- (4) The praxis of finding ways of living with a child with SCD, and concrete ways of sharing that experience and practice, change culture and suggest lay perspectives must be considered as in transition.
- (5) Development of social policy to support new cohorts of young people with SCD in education and employment, and social research to evaluate such policy, are vital complements to newborn screening programmes for SCD.

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