

**THE SOCIAL MEANINGS OF A CHILD
WITH SICKLE CELL DISEASE IN GHANA:
FATHERS' REACTIONS AND
PERSPECTIVES**

by

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ABSTRACT

Sickle cell disease (SCD) is a chronic inherited blood disorder affecting nearly a quarter of a million infants born in Africa each year. Historically it was estimated that over 95% of babies born with SCD in rural Africa died before 5 years old. In Kumasi, the second city of Ghana, where 2% of all babies born have SCD, the newborn screening programme has a survival to five years old of over 95%. Extensive information is available on the clinical aspects of SCD, but there is limited documentation on its social aspects.

Existing literature on SCD is focussed on the US and UK experiences, and takes a predominantly medical perspective. US and UK sociological literature on SCD suggests the importance of the social context within which chronic illness is negotiated, that the impact of SCD is mediated through the experience of racism against minority ethnic groups, and the quality of access to good health services, and socio-economic position within a relatively wealthy overall economy. African social literature on SCD on the other hand has concentrated on anthropologically interesting lay meanings of SCD. Literature on caring for children with chronic illness has focussed on the role of mothers, with little attention to the fathers' experiences. The aim of this study was to produce an in-depth social analysis of fathers' perceptions of SCD, their feelings about the birth of a child with SCD, their role or lack of it in the care of such children and their views for improved care.

Thirty-one in-depth, taped-recorded interviews were conducted with fathers of children with SCD. This data was supplemented by focus groups with nine mothers and seven health professionals. Interviews were conducted in the local Ghanaian language of Twi, and were translated and transcribed by the researcher into English for thematic analysis.

Overall, the thesis emphasises that the experiences of fathers of children with SCD in Ghana can best be explained by a sociological analysis that incorporates an understanding of their expressed perceptions of the challenges of bringing up a child with SCD within a wider socio-cultural context greatly influenced by factors such as the formal and informal stages of courtship and marriage on negotiations of responsibility for children; the integral cultural imperative to bear children; negotiating gender roles in the household division of labour; the structural limitations imposed by a fee-for service treatment for SCD in Ghana; the widespread stigmatisation of SCD as a 'bought' disease; the construction of an understanding of SCD through a supernatural worldview; and the role of organised religion in shaping conceptions of marriage, sexual relations and attitudes to SCD and prenatal diagnosis.

The evidence from this study carries considerable implications for the development of SCD services in Ghana, and indeed throughout Africa, suggesting that the socio-cultural factors affecting fathers' perceptions of SCD should also inform health and social policies for SCD in areas including health care worker education, diagnostic and care services for patients and families, genetic counselling, health education and employment.

Table of Contents

	Page
<i>Title Page</i>	1
<i>Abstract</i>	2
<i>List of Tables</i>	5
<i>List of Figures</i>	5
<i>Abbreviations</i>	6
<i>Acknowledgements</i>	7
Chapter	
One: Introduction	9
. <i>SCD, World Distribution and Prevalence</i>	
. <i>Clinical Considerations and Management of SCD</i>	
. <i>Diagnosis in SCD and Recent Advances in Treatment</i>	
. <i>The Socio-Political Importance of SCD</i>	
. <i>The Research Topic, Aims and Objectives</i>	
Two: Literature Review	30
. <i>Healthcare Provision for SCD in Ghana within an African Context</i>	
. <i>Caring within the Context of Ghanaian Socio-Cultural and Religious Family Life</i>	
. <i>Lay Beliefs about SCD in Ghana</i>	
. <i>Living as a Parent of a child with SCD</i>	
. <i>Caring for a Child with Disability</i>	
. <i>Conclusions</i>	
Three: Strategy and Methods	88
. <i>Methodological Approach to the Study</i>	
. <i>The Sampling Strategy, Process of Sampling and the Sample</i>	
. <i>Method of Data Analysis and their Limitations</i>	
. <i>Ethical Procedures</i>	
. <i>Conclusions</i>	
Four: The Context of Traditional Courtship, Marriage, Children and Family Division of Labour	134
. <i>Traditional Courtship and Marriage</i>	
. <i>Religion and Marriage</i>	
. <i>The Symbolic Value of Children in Marriage</i>	
. <i>Role of Fathers in Childcare and Division of Labour</i>	
. <i>Conclusions</i>	

Page

Five:	The Social Meanings of Health, Illness and SCD	166
	. <i>The Social Concept of Health, Illness and SCD</i>	
	. <i>Knowledge of SCD and its Meanings to Marriage and Childbirth</i>	
	. <i>Learning to understand SCD after childbirth</i>	
	. <i>Social Beliefs on SCD and their Implications for Paternal Care</i>	
	. <i>Conclusions</i>	
Six:	The Social Impact of SCD on Fathers	220
	. <i>The Social-Psychological Meanings of Fathering a Child with SCD</i>	
	. <i>Extending Care to an SCD child</i>	
	. <i>Challenges associated with Paternal Care</i>	
	. <i>Coping Systems in Fathering a Child with SCD</i>	
	. <i>Recommendations for Paternal Involvement</i>	
	. <i>Conclusions</i>	
Seven:	Discussion of Findings within Ghana's Traditional Context, Social Meanings of Health, Illness and Social Reaction of Fathers to SCD	284
	. <i>Context of Traditional Courtship, Marriage,</i>	
	. <i>Children and Family Division of Labour</i>	
	. <i>The Social Meanings of Health, Illness and SCD</i>	
	. <i>The Social Impact of SCD on Fathers</i>	
Eight:	Conclusions and Recommendations	333
	. <i>Conclusions to the Study</i>	
	. <i>Recommendations for Health and Social Policy in Ghana</i>	
	. <i>Original Contributions to Knowledge and Areas for Further Research</i>	
	. <i>Conclusions</i>	
	List of References	369

Page**List of Appendices**

I	Topic Guide with Twi Translations	391
II	Information Sheet about the Study	401
III	Ethical Application	404
IV	Consent Form	411
V	Field Diary	412
VI	Example of the Process of Analysis	413

List of Tables

Table One:	Carrier Frequencies among Selected Ethnic Groups	16
Table Two:	Sources of Data Collected	101
Table Three:	Pen Portrait of the Sample of Fathers Interviewed	108
Table Four:	Occupational Profile of Fathers	110
Table Five:	Living Status of Children of Fathers & Mothers in the Study	111

List of Figures

Figure One:	Map of Ghana showing Kumasi the Research Setting	8
Two:	Okomfo Anokye Teaching Hospital	38
Three:	Patients waiting at the Sickle Cell Clinic-KATH	43
Four:	Tying up of body part due to vasocclusive pain	181
Five:	Chronic splenomegaly (witch pot in belly)	202
Six:	Small-for-age (skinny & lanky-woayε ndwedwe ndwedwe)	203
Seven:	Factors Influencing the Understanding of SCD in Ghana	359

Abbreviations

ECOWAS	Economic Community of West African States
FGD	Focus Group Discussions
GHS	Ghana Health Service
GoG	Government of Ghana
GTV	Ghana Television Network
Hb	Haemoglobin
HCW	Health Care workers
HRU	Health Research Unit
KATH	Komfo Anokye Teaching Hospital
MOH	Ministry of Health
NHIA	National Health Insurance Act
NHIS	National Health Insurance
NMIMR	Noguchi Memorial Institute for Medical Research
NGO	Non-Governmental Organisation
NSSCD	Newborn Screening for Sickle Cell Disease
SCC	Sickle Cell Clinic
SCD	Sickle Cell Disease
SCAG	Sickle Cell Association of Ghana
SCFOG	Sickle Cell Foundation of Ghana
SMS-KNUST	School of Medical Science-Kwame Nkrumah University of Science and Technology
TASC	Unit for the Social Study of Thalassaemia and Sickle Cell
WHO	World Health Organisation

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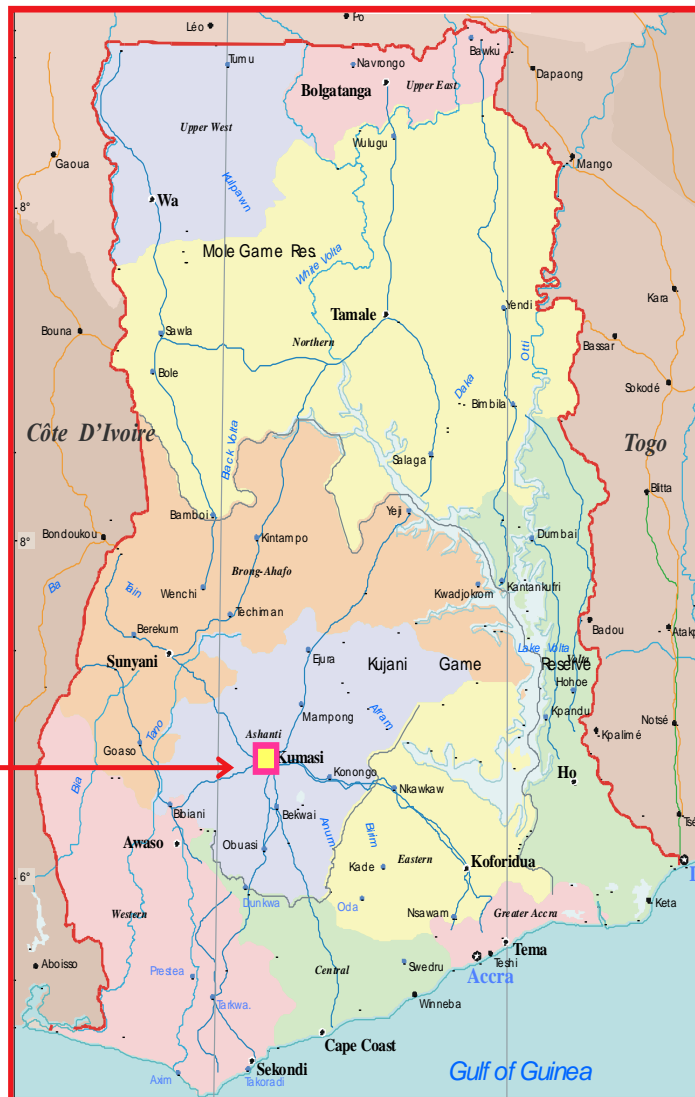
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Figure One: Map of Ghana showing Kumasi

Only site for Newborn Screening for Sickle Cell Disease in Ghana

GHANA

Kumasi



CHAPTER ONE:

INTRODUCTION

Sickle cell disease (SCD) is a chronic inherited disease affecting millions of people worldwide. Though there is extensive information on its clinical aspects, there is only limited documentation on its social and cultural dimensions within Ghana and within Africa more generally. Ghana has no standardised national programme for SCD management despite the established fact that 25% of the population are carriers, that 2% of all babies born (20 births per 1000 live births) have a form of SCD, and that the newborn screening programme in Kumasi, the second largest city, has over 95% of enrolled patients surviving to five years old and beyond (Konotey-Ahulu, 1991; Ohene-Frempong, 1991; Dennis-Antwi, 1997).

In this thesis, findings of a study investigating the social meanings fathers ascribe to SCD as a chronic disease entity are described against the backdrop of the myriad Ghanaian socio-cultural norms, experiences and perceptions that influence fathers' actions and shape their social construction of the disease experienced by their children. Such descriptions are given within an African perspective and, where possible, contrasted to the situation in the UK and USA. Also outlined are recommendations for the development of a comprehensive health and social policy towards improved care for affected patients and families.

This introductory chapter explores the medico-clinical and epidemiological aspects of the disease (SCD) as a means of providing a necessary understanding of the disease

condition and its implications for care by affected families. It achieves this through a review of the distribution and prevalence of the disease within a socio-political and economic context. It further outlines the inheritance, clinical manifestations, diagnostic and treatment aspects of the disease as well as the basis for the choice of the topic. Finally, it provides an overview of the contents of Chapters Two to Eight to facilitate the reader's conceptualisation of the entire thesis.

Sickle Cell Disease, Its World Distribution and Prevalence

Sickle cell disease (SCD) is an inherited debilitating disorder of the red blood cell caused by a mutation of the β globin gene of normal adult haemoglobin A, leading to the production of sickle haemoglobin (Konotey-Ahulu, 1991). SCD encompasses an umbrella of conditions denoted medically as haemoglobin SS, haemoglobin SC, haemoglobin SD disease and Sickle β^0 and β^+ thalassaemia as well as other disease causing phenotypes such as haemoglobin O-Arab and haemoglobin E linking with haemoglobin (Hb) S to produce disease. Generally sickle cell disease is a term embracing all disease states where the Hb S gene is present (Atkin and Ahmad, 1997, Konotey-Ahulu, 1991). Dr J. B. Herrick (1910), a physician in Chicago, first described sickle cells while investigating the blood smear of a Grenadian student who had traveled to the US to study dentistry. However, an extensive series of clinical reports by Konotey-Ahulu (1991), cites good evidence to suggest that the symptomatology of SCD had been recognized in Africa earlier than the 20th century.

Sickle Cell Trait and Inheritance of SCD

An individual is said to have SCD when he or she inherits two abnormal recessive genes (e.g. Hb S and S or C, D, E or β thalassaemia) one from each parent on an equal

basis. Such parents are healthy carriers of the abnormal gene and do not themselves have disease (Ohene-Frempong and Dennis-Antwi, 1995, Anionwu and Atkin, 2001). A carrier state is normally referred to as having a trait. The individual who carries a trait (Hb AS, Hb AC, Hb AE, Hb A β thalassaemia etc.) is one who has inherited the normal Hb A gene from one parent and an abnormal Hb gene (S, C, D, E, β thalassaemia etc.) from the other parent (Sears, 1994).

In situations where a couple are both positive for SCD traits, there are inherent probabilities with respect to the outcome of each pregnancy. In each pregnancy there is a 25 percent chance of having a child with normal Hb gene AA, 50 percent chance that the child will be a trait and a 25 percent chance that the child will have a form of SCD. These probabilities are in no way linked to previous pregnancy outcomes so that it does not matter what genotypes the couple's previous babies had, a present pregnancy has the same three possibilities (Ohene-Frempong and Dennis-Antwi, 1995). In much the same way, it is possible for such a couple to have several children and not produce a child with SCD (Anionwu and Atkin, 2001) or conversely to have more than one child with SCD. Traits are healthy individuals whose status does not change to that of disease over time. Several comparative studies such as Orbell et al. (1977), Ashcroft et al. (1978), Kramer et al. (1978), Heller et al. (1979), Stark et al. (1980), and Colombo et al. (1985) have indicated that sickle cell trait individuals are as normal as their counterparts with the usual Hb gene AA.

Sickle cell trait is perceived as a benign condition which compares favourably with the health status of a non-trait (Sears, 1994). Consequently, people with sickle cell

trait need not be restricted in the performance of any activity that could be undertaken by someone who does not carry sickle cell trait.

World Distribution of Sickle Cell Disease and Trait

Sickle cell disease affects millions of different people worldwide (Sergeant, 1985, Dyson, 1999). This includes people of African origin in the North, Central and South Americas and the United Kingdom, France, Belgium and other parts of Europe. It also affects people within the Middle-Eastern and Mediterranean sub regions such as Greece, Cyprus, Saudi Arabia, and Kuwait. Other important places include Italy, Spain, Turkey, India and Pakistan (Ohene-Frempong and Dennis-Antwi, 1995).

Sickle cell disease is the commonest genetic condition of epidemiological importance to Black Africans (Durosinmi et al, 1995). Historical accounts of the spread of the disease from tropical Africa to most parts of Europe, the Americas and Caribbean attribute it to the Atlantic slave trade in the years 1451-1870 as well as the economic migration of Africans to these parts of the world. However, the journey of the β^s gene is a little more complex than this. First, the β^s mutation occurred at least 5 separate times in separate geographic sites, 4 in Africa and 1 in the India-Saudi Arabia region. This has given rise to the 5 genetically-distinct β^s haplotypes. Of the 4 African haplotypes – Senegal, Benin, Bantu, and Cameroon – it is the Benin haplotype that crossed the Sahara from its West African forest origin to North Africa, the Mediterranean countries and to most Middle East countries including western Saudi Arabia. Eastern Saudi Arabia, India, and Sri Lanka share the Arab-India haplotype. The β^s gene has undergone at least three waves of migration out of Africa. The spread of the Benin haplotype to North Africa, southern Europe and Middle East long

preceded the trans-Atlantic slave trade and probably occurred some time around 1100-200 BC (Dennis-Antwi, Dyson and Ohene-Frempong, 2005). This may have been the first wave of β^s migration out of Africa. Trading routes from West Africa to central Sahara and from there to North Africa (then known as the Maghreb), migration of West Africans to the north as soldiers, traders, or slaves (there were black African servants in the Roman Empire), and invasion of the Maghreb by Greeks, Phoenicians, Persians, and Romans in that period all may have transported the Benin β^s gene to Europe and Middle East (Fryer, 1984). A small part of this migration may have involved East Africans being sent via the Indian Ocean to Arabia as slaves, but the scarcity of the Bantu haplotype in the Middle East makes it unlikely that the β^s gene travelled along that slave route in a significant wave.

The trans-Atlantic slave trade would serve as the second wave of β^s migration out of Africa and its destination was mostly the Caribbean and the Americas with a very small portion to Western Europe. The voluntary migration of Africans [and Asians] throughout the world – particularly to Western Europe – in the past century provided the opportunity for the third wave of migration of the β^s gene out of Africa. During the period of slave trade, it is estimated that out of a total of 9.66 million slaves, 399,000 were imported to British North America, 3.65 million to Brazil and 3.79 million to the Caribbean (Ranney, 1994). Clinics in Greece, Italy, Saudi Arabia, and India were managing SCD in “non-African”, non-black patients long before newborn screening in the U.S. confirmed that SCD is not necessarily a ‘black disease’ (Sickle Cell Disease Guideline Panel, 1993).

The wide ethnic diversity of people with the β^s gene stands as an illustration of

scientific failure to classify peoples as distinct 'races' (Dyson, 1998). Though uncommon, people who would consider themselves of white British descent have also been identified to carry sickle genes (Lehman and Huntsman, 1974) and in the UK it has been claimed by Anionwu and Atkin (2001: 9) that:

“Today patients with SCD range from individuals with blond hair and blue eyes to those with olive skin and straight dark hair to those with dark skin and curly black hair”.

Prevalence

An assessment of the prevalence of the disease worldwide shows that about 300,000 children are born affected each year (Okpala et al, 2002) and that three-quarters of these are born in Africa (WHO, 1994). An earlier observation by Fleming (1989) indicated that each year, 120,000 babies are born with the disease in Africa alone. In comparison, around a 1000 a year are born in the U.S. and 200 in the UK (Anionwu and Atkin, 2001). These comparisons clearly establish that the highest proportion of affected babies are to be found in Africa. However, the current estimates for Africa are probably much higher than stated in the literature cited. In Nigeria, like Ghana, 2% of babies have SCD. With approximately 5 million births per year, Nigeria alone would have 100,000 babies with SCD a year. If the 2% rate of SCD were extrapolated over the 16 countries in ECOWAS, with roughly 10 million births per year, West Africa alone would have 200,000 babies with SCD annually.

Central and parts of East Africa have incidence of SCD similar to that of West Africa whilst the northern and southern regions have lower incidence rates. In the year 2000, there were 29.6 million babies born in Africa. If only 1% of them had SCD, that

would come to 296,000 babies; if the overall SCD incidence rate for Africa were 1.5% (probably closer to the truth) the number of SCD babies would be 444,000 (Dennis-Antwi, Dyson and Ohene-Frempong, 2005).

Although much of tropical Africa has been found to have the gene, the highest gene frequencies have been reported to occur in non-Black populations in Saudi Arabia and India (Livingstone, 1977). Nevertheless, the volume of births of children with SCD in Africa and the large proportion of the overall number of infants with SCD born each year, marks out the distinct position of Africa as a continent epidemiologically and socially important for the study of sickle cell disease.

Prevalence statistics show the high frequency of sickle cell trait among West Africans (1 in 4, or 25%) and the prevalence of Hb C trait among Ghanaians (up to 1 in 6, or 17%). The general picture is that sickle cell trait is more common in Western, Central and Eastern Africa (Ohene-Frempong and Nkrumah, 1994). Tanzania stands out as the country with the highest maximum prevalence rate of 40.5% within a population followed by Nigeria (30.7 %). Somalia apparently has no documented evidence of sickle cell trait. Again, West Africa presents a high concentration of traits with very high maximum rates when compared with the other regions in totality.

The prevalence of SCD in Africa cannot be discussed without a mention of the role that malaria is reported to have played in the genesis of SCD. According to Eaton, (1994), impressive, archaeological, epidemiological and ecological arguments have been raised to associate *Plasmodium Falciparum* – the causative organism for one of

the most virulent human malarials in endemic West Africa - as an exclusive agent of positive selection for the Hb S gene. He further explains that over 2000 years ago, farming activities in the African tropical rain forest led to the appearance of endemic *Plasmodium Falciparum* which is believed to have caused high mortality (20%) within populations (Livingstone, 1971). Consequently, human populations evolved a protective state of heterozygosity through a mutation of the β globin gene in order to reduce mortality due to malaria but which in a hemi-or homozygous state resulted in genetic disease.

Table 1: Carrier frequencies among Selected Ethnic Groups (Source: Anionwu and Atkin, 2001: 12)

Haemoglobin type	Ethnic Group	Estimated Trait Frequency
Beta thalassaemia trait	Cypriots	1 in 7
	Asians	1 in 10-30
	Chinese	1 in 30
	African-Caribbeans	1 in 50
	White British	1 in 1000
Sickle cell trait	African-Caribbeans	1 in 10
	West Africans	1 in 4
	Cypriots	1 in 100
	Pakistanis, Indians	1 in 100
C trait	African-Caribbeans	1 in 30

	Ghanaians	Up to 1 in 6
D trait	Pakistanis, Indians	1 in 100
	White British	1 in 1000

These data bring to the fore the relevance of SCD as a disease of public health importance complicated by malaria in Africa and West Africa. Edington and Laing (1957) found that Ghana, the focus of this research, has 20-25% of its population in the south of the country having sickle cell trait as compared to 10 % in the northern parts where the C trait is more prevalent (20-25%). These findings provide a strong and significant basis that justifies Ghana as a suitable setting for carrying out the study.

Clinical Considerations and Management of SCD

Clinically, SCD patients are susceptible to sickling of their red blood cells resulting in variable, unpredictable and sometimes life threatening complications as a consequence of blockage of the tiny blood vessels that supply oxygen to the tissues of the body (Atkin and Ahmad, 2001). Complications of SCD have been severally reviewed in detail in the medical literature and include severe anaemia, painful crisis, acute chest syndrome, priapism, stroke and other neurologic complications, cardiopathy, renal complications, leg ulcers, retinopathy, splenomegaly, delayed growth and development as well as debilitating bone and joint disease to mention a few (Embury et al, 1994). For the purpose of this introductory chapter, mention will be made of three of the most important complications capable of frequent illness,

disability or death (Anionwu and Atkin, 2001) namely severe anaemia, vasocclusive pain and bacterial infections.

Vasocclusive pain (painful crisis) emerges as the commonest clinical problem of patients and the reason for frequent visits to the emergency wing of hospitals (Serjeant et al, 1981). Patients are episodically stricken with severe painful attacks lasting a few days or one to two weeks (Dennis-Antwi, 1997) and malaria itself is often reported as the precipitating factor in painful crisis in African patients (Fleming, 1989). The frequent recurrence of painful crisis greatly affects the physical and psychological well-being of patients (Shapiro and Ballas, 1994).

Both acute and chronic anaemia are typical features of SCD, as noted by Glader, (1994), Ohene-Frempong and Nkrumah, (1994) and Atkin and Ahmad, (2001). At birth, children with SCD are protected by the presence of large amounts of foetal haemoglobin (Hb F) which prevents the emergence of anaemia (Serjeant et al, 1981). However, this protection is usually short lived as the concentration of Hb F decreases with increasing age so that as early as 2-6 months of age, it is possible to clinically diagnose acute anaemia (Mason et al, 1982). Haemolysis has been reported to be the major cause of chronic life-long anaemia in SCD resulting in overproduction of bilirubin with its associated complications of the liver and biliary tract (Embury and Steinberg, 1994; Glader, 1994).

The third very important clinical complication of SCD is the overwhelming infections patients are prone to (Dennis-Antwi, 1997). Infections are the commonest causes of mortality among infants and young children within the first five years of life and form

an integral feature of virtually every disease manifestation in SCD (Wong et al. 1992; Buchanan, 1994; Ohene-Frempong and Nkrumah, 1994; Anionwu and Atkin, 2001)

A reflection of the clinical manifestation of SCD in Africa shows that there is no fundamental difference between Africa and elsewhere in the world. However, the unique environmental, economic and social conditions in much of Africa provide a background against which the disease projects a picture different from that in the technologically developed nations (Ohene-Frempong and Nkrumah, 1994). For instance, malaria alone has a strong adverse impact on the clinical course of the disease in endemic areas of Africa and is reported to be the commonest cause of morbidity and mortality among SCD patients in Africa (Ohene-Frempong and Nkrumah, 1994). According to Fleming (1989), the life expectancy of SCD patients in Africa is largely unknown and less than 2% of the expected number of children with SCD survived beyond five years of age due to the overwhelming infections they are exposed to and in which malaria plays a significant role. This assertion again strengthens the importance of SCD as a major public health problem in Africa generally and Ghana in particular.

In view of the nature of the disease, management of sickle cell disease requires a holistic approach involving a multiplicity of professionals including paediatricians, physicians, haematologists, urologists, ophthalmologists, orthopaedic surgeons, obstetricians, gynaecologists, nurses, health educators, genetic counsellors and many more (Ohene-Frempong, 1991; Okpala et al 2002). In simple terms, management of sickle cell complications involve the administration of medicines such as antibiotics to prevent or fight infections; analgesics and infusions to reduce pain due to

vasocclusive events; blood transfusions where necessary to correct severe anaemia, and surgery for problems such as chronic splenomegaly and gallstones (Ohene-Frempong and Dennis-Antwi, 1995). Lifelong daily administration of folic acid to promote replacement of red blood cells, and prophylactic penicillin specifically for children between 2 months to 5 years orally, twice daily have been shown to significantly reduce infection due to *streptococcus pneumoniae* (Gaston et al. 1986). Patient and parental education coupled with genetic counselling are also pivotal in effective health care maintenance and future decision making related to childbearing (Smith and Wethers, 1994).

Diagnosis of SCD and Recent Advances in Treatment

Diagnosis of SCD within the laboratory is by the straightforward means of electrophoresis, isoelectric focussing and high performance liquid chromatography (Embury et al, 1994). Results usually suggest the correct genotypic diagnosis with a high degree of confidence (Adams, 1994; Baines, 2005; Dyson, 2005; Mutton and Peacock, 2005).

Prenatal diagnosis and newborn testing are positive advances in SCD management that have enhanced the possible identification of pregnancies at risk of SCD and early identification of newborns for SCD at birth respectively (Embury, 1994). However, the technical developments of prenatal diagnosis must be set against the many ethical, legal and social criticisms that question the right to control the biological makeup of future generations of families at risk for the disease (Powledge and Fletcher, 1979; Gates, 1993; Katz Rothman, 1994).

Some studies conducted on the level of social acceptability to prenatal diagnosis and or premarital testing in Africa, Iran, Cyprus, Greece and Israel have shown high levels of public acceptability for their use. In Cyprus for instance both methods are accepted (Angastiniotis, 1992) whilst in Israel and Iran premarital counselling is the method of choice (Shiloh et al. 1995; Ghanei et al.1997) as it is in Nigeria (Duronsinmi, et al. 1995).

Recent advances in the treatment of SCD have included bone marrow transplantation, hydroxyurea and gene therapy (Anionwu and Atkin, 2001). Bone marrow transplantation offers hope as a cure for SCD, though is it a procedure more commonly used in the management of thalassaemias (Vermylen et al. 1991). As of 1994, worldwide experience with the procedure indicated that a total of 48 people had undergone transplantation with 96% survival, 4% death and 88% disease free survival (Mentzer, 1994). European experience with this procedure is documented to be more extensive than that of United States who started work in the field around the 1980s (Vermylen, 1988; Mentzer, 1994).

According to Johnson et al. (1984), the first bone marrow transplant was carried out successfully in 1983 on an eight year old SCD patient whose condition was complicated by leukaemia. Since then, over 80 patients worldwide have benefited from the procedure with over 90% success rate (Robert, 1994). It is worth noting that bone marrow transplantation is a very expensive procedure costing between \$150,000 – \$200, 000 in the U.S. or even higher if complications arise (Mentzer, 1994).

For this reason it is unlikely to play any major role in the foreseeable future in the alleviation of SCD in Africa. Efforts so far made in Ghana document attempts by a newly set up non-governmental organisation (NGO) called the DWIB Foundation to generate a register of bone marrow donors as a resource for leukaemia and possibly SCD patients in Ghana and nearby West Africa. The President of Ghana inaugurated the Foundation on March 11, 2006 (GTV News, 2006).

Hydroxyurea is a later discovery in the drug therapy of sickle cell patients and was reported to be beneficial to patients during a randomised trial by Charache et al. (1995). This is because the drug had the ability to increase foetal haemoglobin levels in the blood and thereby reduce vasocclusive episodes. The array of benefits to patients included a reduction in the frequency of painful episodes, acute chest syndrome, and blood transfusions, and an improved sense of wellbeing. Unfortunately, it did not impact positively on incidence of strokes and death rate (Charache et al, 1995). The usefulness of hydroxyurea on children is still being studied. However an initial study by Kinney et al. (1999) has demonstrated sufficient encouraging results to permit further research.

Gene therapy is a more recent advancement into SCD treatment and consists of the introduction of a functional β^A globin gene into hematopoietic stem cells of a homozygous affected individual as a substitute for the defective β^S genes (Forget, 1994). So far the therapy, which has been successful in mice, has not been tried on humans due to potential safety problems associated with the use of retroviral vectors as gene transfer vehicles (Miller, 1990). Again such high-tech and expensive

procedures are unlikely to be of immediate relevance to the majority of SCD patients in Africa.

Since 2001, several journal publications have expressed the hope that gene therapy offers for total cure of SCD among humans only if the safety problems could be overcome (May et al. 2000; Bodine, 2003). Most of these scientific advances make interesting reading and offer hope for cure for SCD. Unfortunately however, this hope is limited to the small minority of affected patients who live in Europe and U.S. who can afford to pay for the procedures. Africa and, specifically, Ghana with its high concentration of sickle cell patients stand a tremendous chance of benefiting from these advances, but lack the financial, economic and scientific resources to bring these therapies to the doorstep of affected families. These issues are taken up further in Chapter Two.

In ending this introductory overview of SCD, a brief account on the politics surrounding the disease is provided, with the complexities associated with addressing the public health issues of the disease being discussed.

Socio-Political Importance of SCD

Internationally the issue of ethnicity has been associated with the extent to which resource allocation is made to meet health care needs of minority populations especially in Europe especially the UK (Ahmad and Atkin, 1996) and America.

A study of the literature on the British Health System has shown that though the Government acknowledges that U.K. ethnic minorities have special health care needs, little attention had been given to meet these needs until recently (Anionwu and Atkin,

2001). According to Anionwu and Atkin, mistaken assumptions about limited importance of blood related disorders in debates on health and social issues have resulted in their being relegated to the background of national social policy agenda; thereby reducing the release of funds for development and research.

In comparing this situation to that of Africa, it could be argued that in Africa, the disease prevalence knows no ethnic boundaries and therefore all ethnic groups in a particular country are equally affected. However, it is unfortunate to indicate that the resource allocation to SCD in most African countries is very limited. Major international funding sources are concentrated on communicable diseases (Dennis-Antwi, 1997) thereby diverting policy attention and focus from chronic and non-communicable diseases with a resultant lack of standardised services for affected populations. Again, this issue is further discussed in Chapter Two.

The Research Topic, Aims and Objectives

The need to carry out this research was inspired by a critical observation by the researcher of the social, economic and emotional environment within which families affected by SCD have lived over the years in Ghana and the seemingly limited involvement of fathers in the care of children with SCD. It was also influenced by earlier assertions by Midence and Elander (1994: 78) suggesting the need to further investigate the effects of SCD on fathers. The area of study proposed for this thesis describes the social meanings of a child with sickle cell disease in Ghana in order to understand paternal reactions and perceptions to the birth and care for an SCD child and the implications of such reactions for the development of a comprehensive health and social services for SCD in Ghana. It was hoped that the findings would:

- Provide an insight into the meanings and the sociological implications of being a father of a child with a chronic illness such as SCD within the Ghanaian context.
- Add to the body of existing knowledge on the social-cultural implications of parenting children with chronic illness. Presently, little if any is known about fathers' reaction to chronic illness.
- Support the development of possible strategies for the health and social sector in Ghana in comprehensively addressing the needs of people living with sickle cell disease in particular and chronic diseases in general.
- Provide recommendations for future health and social policies regarding parental roles in sickle cell disease management.

Aims

- To provide a sociological analysis of the meanings of sickle cell to fathers of children with SCD in Ghana.
- To understand and describe the feelings, motives and behaviour of Ghanaian fathers of children with SCD.
- To make recommendations for health and social policy for SCD management in Ghana.

Objectives:

1. To recruit a sample of fathers of children with SCD by talking to a group of mothers through support groups and by use of self-select sampling.
2. To determine fathers' understanding of SCD, their reactions to the birth of a SCD child and the social impact on them.
3. To describe the social and cultural context (including context of traditional marriage, religious beliefs, and intra-family relations) of having a child with SCD in Ghana.
4. To identify and describe the exact roles fathers play in the care of SCD children and the relationship of those roles to the overall functioning of the family.
5. To provide an account of the social meanings of health, illness and stigma and their bearing on fathering an SCD child
6. To evaluate the current social and formal practices in health care, if any, which mitigate fathers' optimal involvement in SCD management.
7. To use the findings to support the proposal of a policy directed at providing a user-centered health and social support services to meet the health and social needs of SCD patients in Ghana.

In order to achieve the above aims and objectives, Chapter Two set outs the existing literature on the health provision for SCD and, where possible, draws specific comparisons between Africa (especially Ghana), Europe (especially the U.K.) and North America. The chapter also outlines the relevance of the socio-cultural aspects of marriage, childbearing, caring, religious and lay beliefs; and family division of labour

to the research topic. A reflection on the politics surrounding health care services for SCD is also outlined as a means to gaining more insight into the dynamic complexity of SCD as a medical, economic, social and ‘racially’ tagged disorder (Anionwu and Atkin, 2001). Such a broad approach is important in establishing the foundation upon which the rationale for investigating the social meanings of caring for a child with SCD in Ghana can be presented and justified.

In Chapter Three, the epistemological approach to the study is outlined, together with its limitations, issues in selection and recruitment of respondents, choice and the rationale for data collection methods. An account of the whole study carried out with thirty-one fathers of children with SCD, nine mothers and seven specialist health workers in SCD is also given. The chapter also reports on the procedure for data analysis, and reflects on the researcher’s identities as a health professional and a known focal person in a support group for SCD, their implications for the study and the relevance of researcher reflexivity in addressing these identities. Moreover, it documents the ethical issues attendant upon this research as a sensitive topic and the steps taken to ensure ethical approval from the Faculty Human Research and Ethics Committee and the relevant authorities within the setting of the research (Appendices 2 and 3).

Chapter Four describes findings of the study pertaining to traditional courtship, marriage, children and family division of labour. It presents respondents’ experiences and perceptions regarding traditional rites for marriage, the meaning they attach to marriage, pregnancy and symbolic value of child bearing, the role of fathers in

childcare, social influences on division of labour in contemporary Ghana, and the extent of religious influence on marriages.

Chapter Five outlines the social meanings of health and illness, fathers' perception of SCD as a chronic disease, and the particular manner in which the birth of a child with SCD comprises a deviation from the ideal cultural notion of health. It also gives account of the depth of knowledge acquired on SCD through family, parental education sessions and significant others. The chapter also draws on relationships between fathers' acquired knowledge and their interpretation of the lay meanings ascribed to SCD. An attempt is also made at describing the lay understanding of how SCD is managed in the context of its perception as a disease of metaphysical causes. These analyses create a better understanding of the social positioning of SCD and the factors underpinning such perceptions.

Chapter Six comprises the final analysis chapter and describes the social impact of SCD on fathers. It does so by addressing five emerging themes. These are i) The social meaning of fathering a child with SCD ii) Extending care to SCD children iii) Challenges associated with paternal care iv) Beyond the horizon of SCD and family relationship v) Coping systems in fathering a child with SCD and vi) Recommendations for paternal involvement. Also described as part of each theme are the implications of the findings for health care and social support provision for affected families in Ghana. In the course of the description interconnections emerge amongst previous experiences with the disease, financial support system available to the fathers, access to factual medical knowledge, social support systems and these

complex contexts interact to help determine the ways in which, and the extent to which, SCD impacts on fathers.

In Chapter Seven, the researcher discusses her findings of the study in the light of available literature, conventional medical knowledge, current health service provision in Ghana, and the situations in the UK, USA and the Mediterranean.

Chapter Eight forms the final chapter of this study and outlines the key conclusions that can be derived from the study and suggests recommendations for health and social policy development in Ghana. Furthermore, it describes the original contributions of this study to existing knowledge on sociological aspects of SCD and suggests further potential areas of applied research.

CHAPTER TWO:

LITERATURE REVIEW

In the previous chapter, an important account of SCD as a haemoglobinopathy was given in a way sufficient to provide the platform for appreciating this current chapter which will focus on the health care, social and cultural burden of the disease in Africa generally and in Ghana in particular. Its focus is on exploring existing literature and taking different bodies of sociological and social policy knowledge that addresses the 1) Level of health care provision for SCD in Ghana, the type of fee-for service payment it is based on, and the paternalistic nature of service delivery 2) Caring within the context of the Ghanaian social and cultural family life and the economic value placed on children; 3) Lay beliefs about SCD in Ghana and the influences of formal Christian religion and spiritual beliefs; 4) Living as a parent of a child with SCD in the UK, USA and Ghana; the gendered traditional division of labour; and cultural arrangements for traditional marriage and 5) The social meanings of caring for a child with disability or chronic illness, and the social impact on fathers of children with SCD in Ghana.

These reviews aimed at strengthening the rationale for investigating the social meanings of caring for a child with SCD in Ghana and its social impact on fathers, present different bodies of knowledge applied to the discrete area of SCD: a condition traditionally perceived within the limited gaze of conventional medicine. Furthermore, the literature supports the need to adequately explain the sociological approaches to the experience of SCD in Ghana towards understanding health issues and thereby

potentially increasing the efficacy of social interventions aimed at improving SCD services.

Methods Underlying the Literature Review

The literature search for relevant information on the topic under investigation took different forms, and involved the use of books, journals, grey literature and specific databases, using key search words. Access to these sources of data was through the Central University Library, recommendations from supervisors and the use of online facilities.

Reference books on SCD as a medical condition and the sociological dimensions to its management were consulted through the search engine of OPAC of the Central University Library. Grey literature referenced included such items as the quarterly and annual reports on activities of the Newborn Screening for SCD in Kumasi-Ghana, the Sickle Cell Association of Ghana; France-Dawson Report of UK and various booklets and pamphlets published on SCD in Ghana, UK and the USA.

Specific databases commonly consulted included electronic collections online, social science (ASSIA), medical (MEDLINE/OVID/NLH PubMed). These sources generated much of the literature on publications on the various aspects to SCD perceptions, experiences and policy directions towards improved services.

Countries of specific focus for the search were Ghana and Africa for a wider focus, UK and the USA with a limited consideration for sources from the Mediterranean countries such as Cyprus and Iran. Dates for selecting references were non-specific and based on relevance of the literature to the topic especially for the medical

literature but efforts were made to keep within the last sixteen years (1990-2006) of publications.

Search words were key to identifying the references, and focused on terms such as sickle cell, culture, traditional marriage, gendered division of labour, social and health policies, childbirth, fathering, chronic illness and lay beliefs etc. These words and terms were used to search titles and abstracts. The theoretical basis for the use of the search words was that a full understanding of the social perceptions on SCD could only be achieved by considering the various lay meanings, cultural, economic and service provision context of father's experiences.

In order to limit or narrow the searches undertaken, qualifying words such as sickle cell, illness, Africa, lay beliefs were consistently keyed into specific databases to ensure focus. Based on the abstracts generated, the full text were accessed in pdf file formats and thoroughly read to assess the methods used and the key findings and conclusions. Over 60% of references used in this thesis were thoroughly read. The sections that now follow outline the relevant existing literature on the research topic.

Health Care Provision for SCD in Ghana within an African Context

Discussions in the previous chapter have established the fact that sickle cell disease is a major health problem in tropical Africa by virtue of its prevalence. Mention was also made of the limited resources available for managing SCD in Africa. To date, the natural history of the disease has not been well studied and very few longitudinal studies have been carried out to assess its impact on public health in Africa (Ohene-Frempong and Nkrumah, 1994).

The life expectancy of SCD patients in Africa is largely unknown. Fleming (1989) in his study of a rural community in Africa, reported that less than 2% of the expected number of children with SCD survived beyond age 5. This finding is attributable to the fact that in most parts of the developing world, including sub-Saharan Africa, where deaths and births are not recorded and a formal system of medical care may be unavailable to most of the population, vital statistics are mainly guesstimates derived from extrapolations, models, common sense and constrained by the need to avoid conflict with previous published estimates (Cooper et al. 1998). Cooper and his colleagues further assert that in the absence of these vital records, local community studies are often used to obtain information about population dynamics such as infant mortality. This insight suggest both the plausibility of Fleming's (1989) findings, but also underlines the fact that the true picture of the disease burden of SCD is largely undocumented in most parts of Africa, therefore making it difficult to make a strong case for the disease to be recognised as one of public health importance. However, more recently Ohene-Frempong (2005) has demonstrated the possibility of improving the survival rate of SCD patients to 95% in Africa through a project-based longitudinal study that enrolls newborns at birth for SCD and provides comprehensive clinical, educational and social support services in Kumasi-Ghana.

It is worth reiterating that comprehensive care of SCD involves a model of health care based on interaction of medical and non-medical services with the affected people (Okpala et al. 2002). Such comprehensive care includes patient and parent information, genetic counselling, social services, infection prevention, nutrition education, psychotherapy, the diversity of medical and surgical specialist care as well as specialised nursing care (Okpala et al. 2002). The main question is: to what extent

do health care services in Africa or Ghana meet these comprehensive criteria for SCD management? To answer this question, an attempt has been made to examine the health care system in Ghana and the facilities so far established for SCD management.

Health Care Services and Care for SCD patients in Ghana

Empirical evidence on trends in health care in Ghana shows similarities to most African countries, where improvements have lagged behind the developed world in most aspects (HRU/MOH, 1998). Modest improvement in certain vital statistics such as infant mortality rates have been observed to have reduced from 133 in 1957 to 55 per 1000 live births in 2002 and under five mortality from 154 in 1988 to 110 per 1000 live births in 1998. The average life expectancy has increased from 45 to 56 years (GSS/MI, 1999; World Bank, 2003; <http://www.state.gov/r13/10/04>; <http://www.ghanaweb.com/GhanaHomePage/general/> 1/12/2006). This rate of change has been slow over the years due to the fact that Ghana has a low per capita income of US\$390 as at 2001, thereby making it difficult for the effective and adequate provision of services including health care (GoG/MOH, 2001; <http://www.ghanaweb.com/GhanaHomePage/economy/statistics.php> February, 2004). Well endowed with natural resources, Ghana, with a projected 2000 population of 20.2 million and a growth rate of 2.5%, has twice the per capita economic output of the poorer countries in West Africa. Even so, Ghana remains heavily dependent on international financial and technical assistance

(<http://www.worldbank.org/data/countrydata> October 2003;

<http://www.unfpa.org/focus/ghana/background.htm> 1/12/2006).

In 1996, Ghana developed a long-term vision for growth and development that would propel it from a low income to a middle income country by 2020. This vision was code named Vision 2020 and implicit in this vision was the goal to maximize the health and productive lives of Ghanaians (GOG, 1997). Of significant interest among the specific objectives to achieve the health goal were to i) Reduce significantly infant, child and maternal mortality rates ii) Increase access to health services especially in rural areas and iii) Establish a health system effectively re-oriented towards delivery of public health services.

Based on the objectives, priority health interventions were selected for focus. Of the selected endemic diseases, SCD did not in any way appear (GoG, 1997). Indeed, SCD has scarcely been regarded as a disease of any public health significance.. The health status of children with serious genetic disorders such as SCD has been submerged by statistics of death from the major childhood diseases in Ghana such as malaria, acute respiratory infections and malnutrition related conditions (Dennis-Antwi, 1997). Of the projected 14,200 babies born each year with a form of SCD in Ghana, most go undiagnosed and probably die young (Ohene-Frempong, 1991) as in the case of Fleming's (1989) findings.

Ghana has no standardised national programme for SCD management despite the established fact that 25% of the population are traits and 2% of all babies born (20 births per 1000 live births) have a form of SCD (Konotey-Ahulu, 1991; Ohene-Frempong, 1991; Dennis-Antwi, 1997). The only organised programmes available are found in the largest cities in the country namely Accra the national capital, Kumasi

and, more recently, Tema, Koforidua and Sunyani through SCAG. Discussions for standardising SCD care nationwide have been revisited as part of a national strategy for policy development in the management of non-communicable diseases in recent times. Since the commencement of this study, the researcher has been selected as a member of the committee working on the SCD policy (Bosu, 2006).

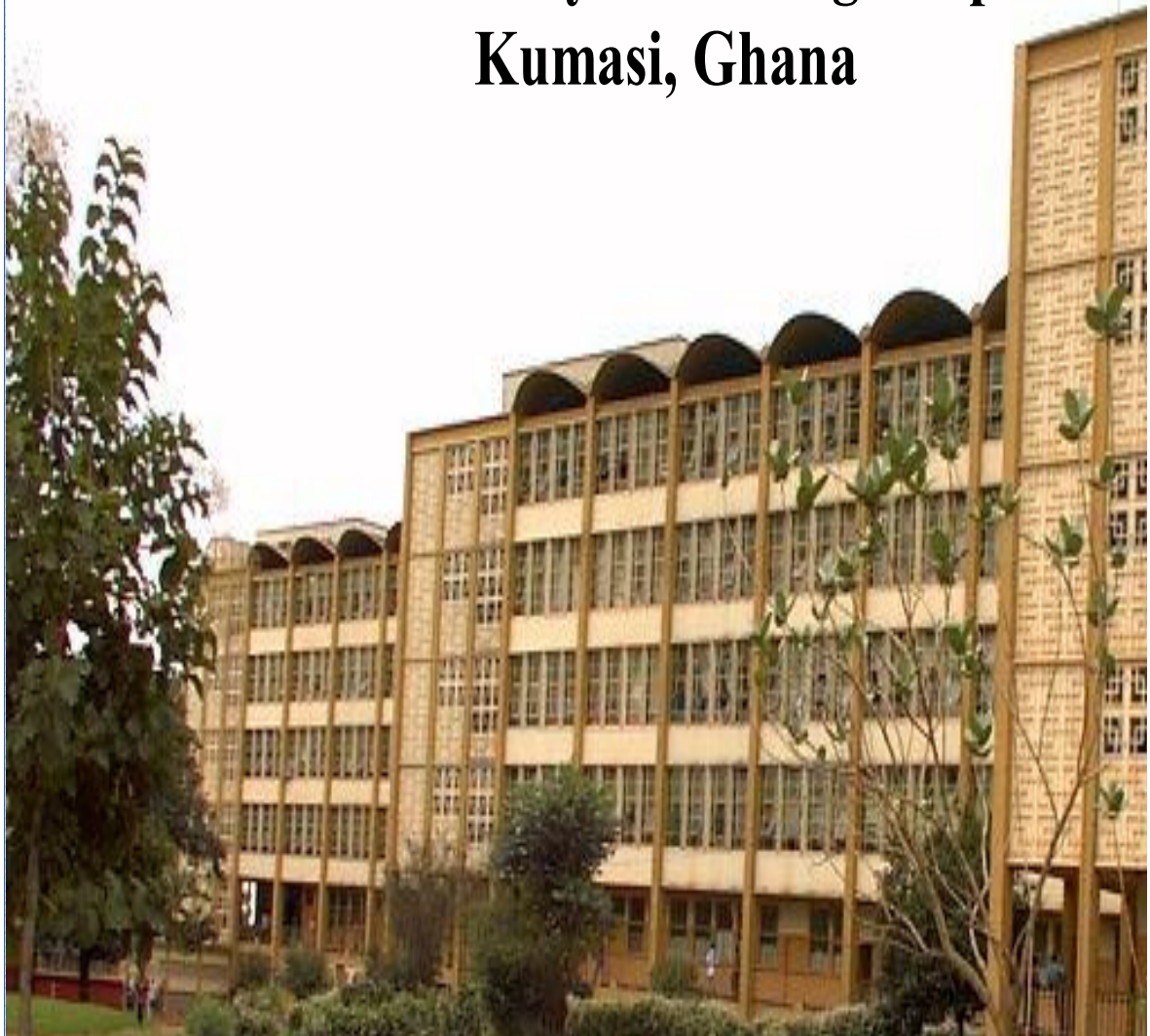
In the 1960s through the initiative of Dr F.I.D Konotey-Ahulu, the first comprehensive SCD programme was established at Korle-Bu Teaching Hospital, Accra to provide specialist care for all patients countrywide. This programme eventually progressed to become the Institute of Clinical Genetics in 1974 (Dennis-Antwi, 1997). At that time, prevailing data on the frequency of hospital admissions for SCD showed that Hb SS patients were admitted 878 times whilst that of Hb SC patients was 529 times. Moreover, 11,110 patients days were spent by Hb SS patients and 4,984 days by Hb SC patients in Korle Bu Teaching hospital between October 1963 and June 1970 for treatment (Konotey-Ahulu (1991). These figures alone testify to the enormity of the problem at that time. Furthermore, until 1992, the facility in Accra was the only one established to provide for the health care needs of SCD patients. With the present increase in population and improved access to health care in the urban and some rural communities in Ghana (HRU/MOH, 1998), the demand for such health services will have increased dramatically.

In the majority of Ghanaian and African children, SCD diagnosis is often delayed and made after several visits to the hospital or clinic with acute illness, rather than early diagnosis by virtue of neonatal screening (Ohene-Frempong and Nkrumah, 1994).

Children who are fortunate to be living in urban and peri-urban communities are those likely to get access to better diagnostic services which are often based on solubility or sickling tests. However, these tests give inconclusive results as they do not distinguish between SCD and sickle cell trait (Adams, 1994). Fortunately in 1992, the Okomfo Anokye Teaching Hospital in Kumasi (see Figure 2) established a SCD programme as a requirement for the commencement of the first ever newborn screening for SCD in Africa. This project was set up as an international collaborative programme funded by the U. S. and Ghana governments through the initiative and foresight of a Ghanaian Professor known as Kwaku Ohene-Frempong, a paediatric haematologist at the Children's Hospital of Philadelphia (Dennis-Antwi, 1997).

Figure Two: Komfo Anokye Teaching Hospital-Kumasi

Komfo Anokye Teaching Hospital Kumasi, Ghana



Screening of newborns in Kumasi began in February 1995 and as at December 2005 the project had successfully screened 196,442 babies born within and around Kumasi and a rural community called Tikrom. Of these, 3,647 (around 2%) were found to have possible SCD with some undergoing further confirmatory testing (Ohene-Frempong, 2005).

This project has been highly successful in establishing that newborn screening could be carried out in a developing country. It has also demonstrated the challenges of implementing the programme within the African milieu (UK-NHS Sickle Cell and Thalassaemia Screening Programme, 2001) It has been instrumental in the provision of specialised health care to SCD patients in Ashanti region and the rest of the regions beyond as well as increasing the survival rate to 95% of enrolled patients. Despite these successes, efforts by the project leaders through national conferences, presentation of statements and meetings with policy makers within the health sector and political authorities to expand the programme nationwide to reach all newborns has not yielded any observable results as at the time of this study. Screening is still performed only in Kumasi, thereby benefiting a few (Dennis-Antwi *-unpublished observations*). To date, medical care for most patients with SCD nationwide is provided through the existing static health facilities found within the national, regional and district health care systems save those in Accra, Kumasi, Sunyani and Tema. As at 1997, 35-40% of Ghanaians, mostly in the rural areas, had no easy access to health care (GoG/MOH, 2001). In Ghana, SCD patients are seen as part of general outpatients reporting daily at the health facilities.

Just like other African countries, an overwhelming majority of these patients attend hospital with acute illness without necessarily having been diagnosed with SCD. A majority are presumed to live and die without the tests necessary to establish correct diagnosis (Ohene-Frempong and Nkrumah, 1994).

Treatment for most of the complications of SCD described earlier on, differ in Ghana and Africa from that of the developed countries. For instance Ohene-Frempong and Nkrumah (1994) report that management of vasocclusive pain are mainly by acetaminophen preparations alone or in combination with oral codeine which physicians assume is enough to reduce pain. However, in the U.S and Europe, parenteral opioids are often used. There are strong disagreements among physicians and haematologists as to the justification for the use of opioids for managing pain in Africa and the Caribbean (Serjeant, 1985; Konotey-Ahulu, 1991). These disagreements have raised the question as to whether patients who live in their 'home' environment are more tolerant of pain than their counterparts who live in Europe and the U.S. Studies to compare pain management with tolerance or satisfaction are needed to effectively address this disagreement, as noted by Ohene-Frempong and Nkrumah (1994). But even this example alone shows the big gap that exists in the use of modern technology and recent advances in the treatment of SCD within Africa, Europe and U.S. These differences, amongst other factors, give the SCD patient in the developed world a better chance of survival compared to a colleague in a developing country like Ghana.

Training of Health Care workers in SCD management

Another important dimension to health care for SCD patients worth discussing is the extent to which health care workers (HCWs) in Ghana and Africa are trained to care for SCD patients and their families. HCWs are introduced to SCD as a haemoglobinopathy during their professional training as students. Experience in SCD management is often gained through exposure to patients on the job. Continuous medical and specialist training is very limited to a few in the cities (Accra and Kumasi) and organised on ad hoc basis (Sackey, 2000). Reference is made to a survey carried out by Dennis-Antwi et al. (1995) to assess the educational needs of health workers and consumers in Ghana prior to the institution of newborn screening for sickle cell disease in Kumasi. In the survey, 22 doctors and 35 nurses in clinical care services were interviewed as part of the total sample. Findings indicated gaps in knowledge about SCD and its management, necessitating the need to organise continuous medical education for doctors and nurses in Kumasi to enable them effectively support the newborn screening programme. These findings are similar to that found among a selected group of midwives in the U.K. by Dyson et al. (1996) and Dyson (2005). It is also strongly supported by Ohene-Frempong (2001) in a presentation he made on the experience of quality management of SCD in Ghana for the UK-NHS Sickle Cell and Thalassaemia Screening Programme. In his presentation, he stated that the importance of training for health staff at all stages of a screening programme is paramount to quality management of SCD in Ghana.

Another challenge to the training of HCWs in SCD management is the limited and narrow provision for skill-mix in health care management in general.

Though there is a very high doctor-to-patient ratio ranging around 1: 10,000 in urban areas and 1: 14,000 in rural areas ([partnershipvolunteers.org/Ghana, 2005](http://partnershipvolunteers.org/Ghana)), there is limited skill-mix that would permit health workers other than doctors to provide care. Currently, certain cadres of nurses (Medical Assistants, Midwives and Community Health Nurses) in Ghana are allowed to offer basic health care services in communities and clinics as part of the primary health care strategy. This situation reflects the analysis of a number of authors (Freidson, 1970; Johnson, 1972) who have argued that medicine creates and maintains itself as a profession in order to control the terms and conditions of its work, thereby subordinating other professions in the health sector (Davies, 1995).

Parent and Patient Education

“Sickle cell disease is a complex condition that affects the patient, the family and the patient’s and family’s relationship with health care providers and the community. It is imperative that teaching skills necessary for coping with this illness begin at the same time of diagnosis and continue through out the life of the patient, and providers recognise that including the extended family and the community in the education process will ensure the most positive outcome”.

NIH Publication No. 02-2117: 53

The success of any comprehensive care programme for SCD patients and their families is heavily reliant on parent and patient education (Dennis-Antwi, 2000). This is because educational programmes are largely rooted in encouraging affected persons to comply with care and to positively take control over their lives (Dennis-Antwi, 2000; Okpala et al. 2002). Most of the SCD-related information received by affected people in an organised and consistent way in Ghana is likely to be from the centres in Accra and Kumasi. In Kumasi, a comprehensive educational programme to support the newborn screening programme (NSSCD) was established under the direction of

the researcher of this study, then Education and Counselling Coordinator on the project.

Figure Three: Patients waiting at the Sickle Cell Clinic in KATH



As part of educational activities, mothers of newborns identified to have SCD are enrolled to receive continual education and counselling on health care maintenance for their babies. Public educational programmes are also organised to increase public awareness about SCD (Dennis-Antwi, 1997). It must however be stated that in other parts of the country, limited programmes may be organised on ad hoc basis at schools and in churches as part of individual or collective initiatives by health workers or community members with special interest in SCD such as Nurses Christian Fellowships.

SCD is a chronic condition for which treatment for total cure is inaccessible to most patients because of cost implications (Mentzer, 1994). Okpala et al. (2002), in their article on comprehensive care of sickle cell disease, stressed the benefit of educational information being provided in simple language by specially trained nurses. They indicated that such a provision enables a crucial interaction to take place in a more relaxed environment than would be possible for a doctor to carry out. Unfortunately, most patients, whether in Ghana or elsewhere in Africa, do not have access to such services. This is because a majority of nurses do not have that special training. SCD training is largely confined to the orientation they receive as student nurses in school. There is hardly any continuous medical training for nurses in Ghana on haemoglobinopathies. This is probably because SCD is not perceived as a disease of sufficient public health importance. As a result, patients and families go through a lot of untold hardships to live with the disease (Dennis-Antwi et al. 1995; Dennis-Antwi, 2000).

Having provided a background to the challenges to patient and parent education within the health sector, the next section examines the aspect of social support and what facilities exist for Ghanaian SCD patients and their families.

Social Support Services

“A user-centred health service would recognise that when people have health problems they do not just have clinical needs but emotional, psychological and financial needs”.

(Hogg 1999: 4, cited in Anionwu and Atkin, 2001: 93)

In this concluding part on health care provision for SCD patients, a brief account is given on social support services as a means to place further into perspective the plight of affected people in Ghana. So far in the discussion, a vivid picture of limited provision has been provided, suggesting that SCD management in Ghana is largely unorganised and uncoordinated (Dennis-Antwi, 1997), and even where there is an organised system, it is concentrated in just the major cities of the country. This ad hoc and patchy nature of service provision also characterised early UK provision for SCD (Prashar et al, 1985). Meanwhile, other UK commentators have pointed out that SCD patients have emotional and financial needs that must be addressed through the provision of efficient health and support services for effective management (Hogg, 1999: 4).

A similar statement with same implications has also been made by Smith and Wethers (1994), reflecting the U.S. situation to the effect that vocational and social assistance are often required by sickle cell patients and their families and that it is important for health care workers to recognise this and offer support when required.

In the African situation, a different system prevails in that most governments do not recognise sickle cell as a disease of public health importance as indicated in previous discussions. Certainly the environmental, socio-economic and political conditions in most African countries complicate the allocation of resources to the health sector (<http://www.worldbank.org/data/countrydata.October,2003>).

In much the same way these conditions combine to create a clinical picture of SCD much worse than the technologically developed countries such as U.K and U.S. (Ohene-Frempong, 1994). Most health care workers in Africa are not adequately trained to even recognise these needs. Patients are largely seen and managed as part of general out-patients care (Dennis-Antwi et al. 1995; Dennis-Antwi, 1997). Emotionally, they suffer a lot from victim-blaming, ridicule and helplessness not to mention the stigmatising effects of some lay beliefs about the disease (Dennis-Antwi et al, 1995, Dennis-Antwi et al. 2005). It is not uncommon to find that most SCD patients are unemployed and therefore cannot afford their care (Konotey-Ahulu, 1991; Dennis-Antwi et al. 1995; Anionwu and Atkin, 2001). This is not to deny the social support problems that minority ethnic populations experience in the developed world, and the struggles that have been undertaken by community activists that have led to some levels of improvement (Hill, 1994; Ahmad and Atkin, 1996; Oliver, 1996; Atkin et al. 2000; Anionwu and Atkin, 2001). However, for African and Ghanaian SCD patients the services are required right in their home environment, where immediate experiences of racism and issues of minority status do not apply in the same way.

In Africa the disease is not so bound up with one's process of ethnic identification, but rather by lack of recognition as an important disease worth addressing by African governments when compared with other services competing for the same meagre resources (Scott, 1971; Dennis-Antwi, 2005).

Health care financing in Ghana years after independence remains a huge burden for individuals and families (Government of Ghana, 2001). Despite government subvention to reduce the burden of health care costs, costs of care have risen, and continue to place a large burden on the individual Ghanaian, resulting in inequalities in health care financing and access (Government of Ghana, 1997). Consequently, as part of Ghana's Vision 2020 initiative, increasing financial access to health care was considered and made central to the Medium Health Strategy and to the Programme of Work within the Ministry of Health. An exemption budget was established for paupers and decentralised to service delivery points (Government of Ghana, 2001). Though there were guidelines to direct the use of these funds, practically, their release at the service delivery points were at the discretion of the health care managers of the facilities (Government of Ghana, 2001). Most often, SCD patients, a majority of whom cannot afford their health care in Ghana do not benefit from it due to an impression bordering on fear that if SCD patients are made to benefit as part of a standing policy, their cost of care alone will consume the entire allocation to the service delivery point. This seems to the researcher to lie behind the reluctance to commit funds officially for SCD.

Despite all these difficulties, social support services do not actually exist in Ghana for persons with SCD. There have been few instances where individuals have benefited from the benevolence of philanthropists and kind considerations of health care managers. The current Ghanaian Government has implemented a health insurance scheme supported by the international agencies for individuals to buy into appropriate schemes to finance their health. In 2003 the Ghana Government passed the National Health Insurance Act 650 (GoG, 2003) to meet international requirements, thereby bringing into law the establishment of various mutual health insurance schemes (NHIS) at the community, district, regional and national levels to facilitate the financial accessibility to health care. As at January 2006, 107 out of 127 registered schemes had become operational. Each scheme has a mandate to operate a basic minimum package that allows beneficiaries to access basic care at contracted health care facilities (NHIC, 2006). Currently it is not very clear what minimum package SCD patients enjoy and the extent to which they are covered for complications of the disease such as organ problems and their related surgical interventions.

The Sickle Cell Association of Ghana (SCAG), a patient support group formed more than twenty years ago, was formally inaugurated as a non-governmental organization in May, 2004 (Ohene-Frempong, 2004). Currently there are five branches of SCAG: two are located in Accra and Tema both in the Greater Accra region, the third is located in Kumasi in the Ashanti Region, the fourth in Sunyani whilst the last and recent is in Koforidua. . SCAG and the Sickle cell Foundation of Ghana (SCFOG) are leading the effort to influence the Government and the wider health sector to commit themselves to the cause of people with SCD.

The SCFOG is a registered non-profit, non-governmental organisation (NGO) set up in 2004 with a vision to help create a situation where everyone with SCD or its related conditions in Ghana is properly diagnosed, offered education, counselling and modern medical and psychosocial care (Ohene-Frempong, 2004).

The researcher has worked extensively with these support groups in Ghana and has found among other things that the organisation of these support groups have been highly dependent on the personnel and resources of the two organised SCD programmes found in Accra and Kumasi (Dennis-Antwi, 2000) thereby strongly suggesting that the creation and organisation of support services in Ghana requires a dedicated team of people including health workers who are prepared to commit themselves to reach out to these affected groups in the face of limited, if any, support from the government sector. The subject of social support services has been further discussed under the section 'Living as a Parent of a Child with SCD in the UK, USA and Ghana'.

In summarising this section on health care provision for SCD in Ghana within an African context, it can generally be stated that the harsh socio-economic and environmental circumstances prevailing in affected countries, including Ghana, limit the allocation of resources to health care in general and SCD management in particular. What worsens the situation though is the fact that African governments, especially in the sub-Saharan region, do not recognise SCD as one of public health importance. Indeed, there are no reliable data on morbidity and mortality to justify its consideration by policy makers.

The experience of North America and the UK suggests that if SCD management in Ghana and Africa were to encompass specialised clinical services, improved access to care and comprehensive social support services, then people with SCD would be enabled to lead relatively normal lives.

In the next section of the literature review, the Ghanaian social, cultural and religious family life and how it impinges on caring for affected persons with SCD is examined.

Caring within the context of Ghanaian Social, Cultural and Religious Family Life

The last section reflected on health care provision for SCD patients, the gaps that exist in such provisions and their implications for SCD management. In this section the review of existing literature continues with a focus on caring within the Ghanaian family structure. Social, cultural and religious dimensions to family life are also discussed and related to their implication for care of affected persons with SCD.

To begin with, Ghana has a rich and diverse culture that has persisted over the years, much through oral tradition. Culture here is used in the context of the ways of life, beliefs and attitudes of the people of Ghana (Oxford Advanced Learner's Dictionary, 2001). The Ghanaian culture is diverse in the sense that it is greatly influenced by the ethnic group that a person originates from though, as noted by Kelleher and Hillier (1996) in the UK context, there are certain areas of commonality that justify the continued use of the term culture. This is because there are likely to be continuities as well as differences across different ethnic groups.

This statement is true for the whole of the Ghanaian culture where ethnicity was manifested and regarded in a variable, elusive and episodic manner until recently in 1994 when ethnic differences fanned conflicts in the northern part of the country (Lentz and Nugent, 2000) thereby awakening peoples consciousness to their ethnic identities and a sense of belongingness that must be guarded.

Usage of the term ethnic group in this discussion means a group of people who identify with a common primary bond deeply rooted in the past and drawing on a common history, culture and language (Van den Berghe, 1981). There are about 100 ethnic divisions in Ghana characterised by different cultures and languages. But the majority of the people of Ghana today can be classified into 5 major groups- Akan (the largest group-44%), Ga-Adangbes, Ewe, Gonja and Mole-Dagbani (Kuada and Chacha, 1989). However, within these broad ethnic categories there are many diverse languages. Ghana is highly multilingual consisting of about 60 language groups. Some of these language groups may broadly be comprehensible to one another, whereas others may have little or no overlap in mutual understanding. Meanwhile, owing to the colonial history of Ghana, English is the official State language (Salm et al. 2002).

Urbanisation and modernisation over the years have resulted in a current Ghanaian population that is highly ethnically diverse. The various ethnic groups have been exposed to each others' culture and have adopted some similarities in habits such as that of eating, language and dressing. As a result, most Ghanaians are bilingual and there is a degree of cultural homogeneity across the country (Salm et al. 2002; Kuada and Chachah, 1989; Kondor, 1993).

The Ghanaian Culture

The Ghanaian culture is constituted by ceremonies celebrating family life and rites of passage, festivals bringing people of communities together, religious holidays to strengthen common spiritual bonds, and national holidays (Salm and Falola, 2002). The cultural beliefs and practices of a particular ethnic group direct the celebration of these ceremonies including birth, marriage, puberty, even death, and more importantly they influence health (Sarpong, 1974; Kuada and Chachah, 1989; Kelleher, 1996). Furthermore, in the performance of these ceremonies there are expectations of each individual member of the family or ethnic group. These expectations may be implicit or explicit and most often are socially derived and maintained (Burr, 2003).

Marriage and childbirth are the two most important cultural expectations of every young adult. There must come a time in the life of the Ghanaian when he or she is expected to marry and bear children to continue the lineage. Let us briefly look at marriage in Ghana in order to put childbearing and childcare into an appropriate perspective for the management of SCD within a broader social context.

Marriage in Ghana is an institution that brings both families of the would-be-couple together and to that extent is *not* regarded as a private relationship between the two (Kuada and Chachah, 1989). It is considered too important to be left entirely to the couple because it is the beginning of a new lineage or community and the blessings of the elders and ancestors must be sought.

In times past, finding partners for sons was through arrangements conducted by parents in order to ensure that their sons get 'good' wives. These arranged marriages focussed on family considerations rather than personal ones and were intended to link families together for political, economic or social reasons, and often love was not an important issue (Salm and Falola, 2002). This therefore gave limited opportunity, if any, for courtship between the would-be-couple. However, the common occurrence in contemporary Ghana is for a young man to identify the partner, court her for a variable period depending on their mutual compatibility and readiness of the man to find a life partner.

If the man is happy with the young woman, he will inform his parents about it. They would then investigate (often a role played by women) the background of the young woman to satisfy themselves that she is a good choice (Kuada and Chachah, 1989, Salm and Falola, 2002). The young woman's family will also ensure the suitability of the man through similar means. In urban communities where both families are not known to each other, couples work hard for instance by lobbying through a respected family member or a very good friend to convince their families that they have made the right choices. Other means include bringing the partner to family gatherings and meetings to introduce her and to give the opportunity for relations to find out more about her (physical presentation, hopes, aspirations, language, attitudes to service, public relations etc). Evidence of chronic ill-health such as SCD or frequent misfortune during the familial investigation will make the woman an unwelcome choice and the young man will be dissuaded from marrying her (Kuada and Chachah, 1989).

Since in the Ghanaian culture, it is a man who marries a woman and not vice versa, the marriage preparations will be curtailed if the man, for any such reason, decides not to proceed with the marriage. It is speculated that one of the major reasons why Ghanaian families hide the presence of SCD from people within the community even to the point of denying results of testing is to avoid stigmatisation with its consequence effect on marriage. Katbamna et al. (2002) in a study of perceptions of disability and care-giving relationships in South Asian communities in the UK reported that stigmatisation is enough reason for families to deny the existence of a chronic illness in their child or choose to keep it a secret. This study examines whether these reactions of denial, secrecy and feelings of stigma also apply in the Ghanaian context.

When both families are happy with the would-be-couple, a date is agreed on for the performance of customary marriage rite which takes different forms in different ethnic groups and may range from the simplest to the most elaborate and interesting ceremonies. In most Akan families, the man performs what is literally referred to as 'Knocking Rites' as a prelude to the main marriage ceremony. This a brief arranged meeting between the two families to ask for permission for a prolonged courtship or to confirm from the young woman's family that they agree to the proposed marriage between their son and their daughter prior to an impending marriage. The performance of the marriage ceremony after the knocking rites may be immediate or later. However, knocking rites no matter how prolonged (a situation popularly discouraged) is not considered as marriage between the couple. The consummation of marriage entitles the husband to have his wife leave her home to go and stay with him

(Sarpong, 1974). This type of marriage represents more than 80% of conjugal marriages and is recognised by law as among the three main types.

The other legal marriages include Marriage by Ordinance which permits only monogamous marriages; and the Mohammedans Ordinance which permit polygyny just as customary marriage (Salm and Falola, 2002). Present day urbanisation, education and Christianity (Van Ness, 1999; Coyne-Beasley & Schoenbach, 2000; Luginaah et al. 2005) have played major roles in producing a marriage contract performed at two levels where after the customary marriage, the marriage by ordinance is also carried out. Note that marriage by ordinance cannot be performed without the customary marriage. But the latter alone is acceptable and recognised. Genetic counselling before marriage; a concept perceived as good practice in Western countries (Anionwu, 1993; Atkin & Ahmad, 1998) is, however, still alien within the Ghanaian culture. Its practice is limited to churches with extensive influence over their congregations (Garner, 2000).

Co-habitation and premarital sex without the performance of a customary marriage is frowned upon by the community and it is disadvantageous to the woman (Hendrickx et al, 2002). This is because traditionally she not recognised by the man's family and could be denied all privileges and rights in times of crisis, even when children have been born through such a relationship. Should a child with an illness such as SCD be born to such a couple, the man could easily walk out on the woman and leave her helpless (Boateng, 1996). This study investigates if such situations exist and determines the extent to which such fathers have been able to meet the needs of the children especially in the area of health care and social support.

After a happy marriage contract, all members of the family wait expectantly to see the woman pregnant.

Child Bearing, Family Life and Caring for a Child with SCD

Childbearing is considered an essential component in every Ghanaian marriage. As motherhood is the ultimate underpinning of a Ghanaian marriage, barrenness is the worst state in which a Ghanaian woman can find herself, especially among peoples of matrilineal lineages. Childless couples are held in high contempt in Ghana, though modernisation is slowly changing the trend and certain families are somewhat more accommodative (Sarpong, 1974). Evidence from a study by DeRose et al, (2002) in Ghana, tends to suggest similar sentiments. As a result, a couple's inability to bear children is of grave concern not to them alone but to the wider family as a whole (Ebin, 1982; Cornwall, 2001; Geelhoed et al. 2002; Richards, 2002).

Voluntary childlessness (Gillespie, 1999, Wretmark, 1999), a concept that is fast becoming acceptable in the Western world among higher income groups, is highly unacceptable in the Ghanaian and African context. Childlessness breeds lots of familial conflict and bitterness between the woman, often blamed as the cause, and her in-laws, sometimes resulting in physical assaults. It is perceived both as a personal and a public problem and families go to great lengths to use a combination of biomedical, traditional and religious remedies to solve infertility (Olu Pearce, 1999).

Childlessness will commonly motivate a man to practice polygyny or open extra marital sexual affairs over which the childless woman has little say, or he may request a divorce (Salm and Falola, 2002). This occurrence is generally found in all the Ghanaian cultures.

Therefore, the birth of a baby to a socially recognised new couple is welcome news and a great relief to the couple and their wider family. The arrival of the child ushers the couple into a supposedly responsible family life of caring for the child until it assumes adult status. The great expectation of the couple is that they have a strong, healthy and normal baby to nurture into adulthood. However, this seemingly happy news changes when the child begins to show signs of disease and frequent ill-health, as would be the case in a child living with SCD.

The parents reportedly become devastated, probably because of a previous experience with the disease, reaction from immediate family members or close friends, or learned experiences of the complexity of the disease over the proceedings years and the implications of parenting a child with SCD. Consequently, the information is kept as a family secret as much as possible (Shiloh et al. 1995; Katbamna et al. 2000).

The family is the most basic social unit in Ghanaian societies and provides for the maintenance of social security (Boateng, 1996; Salm and Falola, 2002). Attention must be drawn to the fact that the definition of family varies in the Ghanaian social context. It may range from father, mother and biological children (nuclear) to that of an extended one including nephews, nieces, cousins siblings, aunts, uncles and grandparents.

These extended kin may be permanent occupants with the couple or may operate a system of rotation between their home and that of other family members for social support (Brown, 1996; Salm and Falola, 2002). In this day of rapid urbanisation, modernisation and industrialisation, the family concept has undergone transformation, especially in urban communities, to include only the nuclear family within the household itself, whilst maintaining contact with the extended family members (Boateng, 1996). Whatever the type of family a child may be born into, the family is regarded as having a responsibility to provide the basic needs of life namely food, clothing, security, shelter and care when sick. The family is also expected to socialise the child, enforce norms and laws, instil religious and moral practices, transmit cultural heritage and develop in the child a sense of intimacy and belonging to a people with whom he or she shares secret things (Boateng, 1996; Brown, 1996; Mensa-Bonsu and Dowuona-Hammond, 1996).

At this point it will be useful for a clarification of the terms mother and father within the Ghanaian context. Each term can be defined biologically and socially. Biologically, a mother or father is one who is the natural parent of the child (Mensa-Bonsu and Dowuona-Hammond, 1996). The social definition applies to a situation where a child has been adopted customarily or legally by the woman or man in the face of death, abandonment, disability or negligence on the part of the biological parent(s). The biological parent may or may not be a relation of the child's new parent. Whether the child is a natural offspring of the parent or an adopted one, there are legal rights and responsibilities flowing from that status. This includes the right to adequate health care among others (Mensa-Bonsu and Dowuona-Hammond, 1996).

Unfortunately, reports from studies carried out on Ghanaian marriages have tended to show that there are several factors militating against the expectations of 'social parents' to provide for the basic needs of their children (Oware-Gyekye et al, 1996; Brown, 1996; Boateng, 1996; Mensa-Bonsu and Dowuona-Hammond, 1996). Notable among these are gender roles, breakdown of marriages and economic factors.

Fatherhood, Fathering, Traditional Division of Labour and Ghanaian Marriages

Fatherhood and fathering are socio-cultural phenomena generally under-explored when compared with motherhood (Barclay and Lupton, 1999; Sunderland, 2000; Salm and Falola, 2002). Historically and internationally, fatherhood has undergone changes though these changes are incomparable to that of motherhood. These changes have evolved from a last century model of strong breadwinner type father and a primary caregiver mother in the home, to a current model of negotiated and shared gender responsibility in parenting and household division of labour especially in the Western world such as the UK and USA (Lewis, 1992). Reportedly, men as part of an evolving new role in fathering are showing increasing interest in spending time in play, companionship and 'being there' for their children.

Brannen and Nilsen (2006) report of three models of fathering namely: 1) work-focused fathers who are more inclined towards less involvement in fathering due to work ethics. 2) family men who, though they are bread winners, are usually present in the home and place high value on 'being there' and 3) the hands-on fathers who have never been main bread winners and have a negotiated a new role of heavy involvement in childcare.

Traditionally in Ghana, fathering assumes the conventional first model described by Brannen and Nilsen and this is heavily influenced by the clear distinctions in gender roles which have persisted over centuries in Ghana and much of Africa despite changing global trends in family structures, diversity and childcare (Featherstone, 2003). According to both Brown (1996), and to Salm and Falola (2002), the man in Ghana is seen as the head of the household and the breadwinner for the family. He has a final responsibility to provide for the welfare of all in the house. The woman's traditional role is the day-to-day care of children and the provision of domestic services. From a young age, most Ghanaians acquire a social understanding of gendered activities in domestic work and this applies regardless of the educational status of the woman.

When a child is born, the man's role of fatherhood evolves into an emerging responsibility of fathering to ensure that the family has shelter, food, clothing, education and sustained healthy states. In view of these traditional roles men often have advantage over women financially. The Ghanaian woman is often disadvantaged in the allocation of family resources and opportunities, resulting in lack of education and limited economic power. Most often men's economic power accords them superiority (Pahl, 1989) and women may have to seek approval from them to obtain financial assistance from banking institutions for economic ventures. In situations where the woman has been empowered to gain economic and financial freedom, it is common for husbands and wives to keep their financial resources separate, in contrast to what is practiced in the Western world (Oware Gyekye et al. 1996; Salm and Falola, 2002).

On the other hand, Western culture has so permeated the more affluent urban areas that family life assumes a blend of the Western and Ghanaian culture. In such homes the couple share duties and practice a more egalitarian decision making process (Berhane et al.2001). Sharing of duties may include some aspects of support in childcare based on the willingness of the man to get involved. The woman cannot force the level of involvement. It is uncommon to find men participating in domestic work such as cooking and cleaning if their wives are present (Salm and Falola, 2002).

Generally, the changing family patterns and economic trends have enabled some women to be economically independent and to be heads of their own households despite divorce, single parenthood and widowhood. Despite the constraints on them, educated women are able to rise to high status through their professions and achieve economic self-determination so that they do not entirely rely on their husbands to provide for the house (Salm and Falola, 2002). Often, the economic pressures and the wider family role of men to provide for their nuclear and extended families have resulted in the evolution of shared financial responsibility by the couple. There are even instances where the woman is financially stronger than the man. A study by Pahl (1989) of money and marriage in British society argues that even in families where the couple are receiving same income, what comes to the woman for house keeping may vary from home to home and remains highly dependent on the man's willingness to give. Boateng (1996) reports that the breakdown of marriages partly contributes to the emergence of the recent increase in single parenthood in Ghana. Divorce, widowhood, desertion and job transfers are the major contributors to single parenthood. He further states that single-parent families headed by women, which form about three-quarters of the total, are more financially vulnerable families.

Some families have been thrown into chaos as fathers, following the breakdown of marriages, have abdicated their parental responsibility of children. This scenario creates a frightening picture for a SCD child who may be found in such circumstances. Studies already carried out in the past have suggested that marital conflicts and divorce are rife in families affected by SCD (Midence and Elander, 1994; Eddy and Walker, 1999), though these studies may not have been based on valid comparisons and may be based on situations where comprehensive services for SCD are not in place, and where therefore the cause may more appropriately be conceived as from lack of support (a social model of disability) rather than intrinsically (Oliver, 1996) related to SCD in the family (a medical model of disability).

Religion in Ghana

Religion plays an important role in the life of most Ghanaians. There are two forms of religion. One is traditional (indigenous) religion and the other is orthodox religion. Traditional religion is the worship of a supreme being through an inanimate or animate medium such as trees, elephant, carved objects mountains and rivers. Indigenous religious beliefs and practices are dynamic and change depending on the needs of society. It influences the way that Ghanaians see the world and their place in it. Almost all Ghanaians regardless of class or education are affected by it consciously or unconsciously. The presence of orthodox religion such as Christianity and Muslim religion has greatly influenced indigenous beliefs and their practices (Salm and Falola, 2002).

Christianity is the most popular religion in the southern and central parts of Ghana and presently commands the highest percentage of devotees to organised religion in the whole of West Africa.

The Muslim religion has a longer history in Ghana, but does not attract as large a following. The Christian religion, especially that of the Charismatic and Pentecostal churches, have increased in popularity, arguably because of their ability to blend with local cultural practices, intensive powers and inclination towards protecting their members by institutionalising preventive health programmes (Elifson, Klein & Sterk, 2003; Luginaah et al. 2005). Their beliefs in evil forces and divination, together with the dynamic and expressive nature of their services, have been prime reasons underpinning their attractiveness. These churches have great influences on the daily lives of their members. They play significant roles in the marriage of their members and ensure that members marry based on their rules and regulations. Some churches have adopted responsibilities of ensuring that a would-be couple will carry out certain basic laboratory investigations to assess their status before approving of their marriage after counselling such as common in Cyprus (Angastiniotis, 1992). Notable among these investigations are sickle cell and HIV/AIDS status.

There are two outcomes of decisions to marry based on positive results of sickle cell testing. The church, through their marriage counsellors may decide to dissolve the marriage to avoid the possible birth of a child with SCD, or they may throw the decision to the couple to make. These findings are contained in a study carried out by Dennis-Antwi et al. (2001) to investigate the need for a culturally sensitive genetic counselling in Ghana as part of newborn screening for sickle cell disease. Another

finding of the study is the tendency for Ghanaians to attribute the birth of the SCD child to the will of God and will therefore care for them to the best of their abilities. Implied in this belief is the ability of God to totally heal the child of the disease. Such is the power of religion among Ghanaians.

In summary, caring within the context of Ghanaian social, cultural and religious family lives, can be argued to portray children as integral to most Ghanaian marriages and therefore the birth of a newborn is greatly treasured. However the expectation is that the child is a normal healthy one. This expectation does not make a SCD child very welcome due to the known financial and care-giving necessities that this will place on the parents.

Also noted is the moral imperative to care for any child even in the face of SCD. The right of the child to health care cannot be the subject of any moral ambivalence on the part of the care-giver because, even in the absence of the biological parents, it is possible for other members of the family to take up this responsibility. On the other hand, changing family trends suggest that some fathers do abdicate their parental responsibilities, thereby making it economically difficult for female single parents to meet the basic needs of their children. Religion has also been reported to play pivotal roles in the day-to-day life of individuals and even influence their potential to have children with SCD. This study considers the extent to which this wider cultural context impacts on SCD management in Ghana and its implications for social policy.

The next section looks at another social aspect of sickle cell disease that has potential for influencing acceptance of children with SCD among families and their

commitment to care for them, and that is the lay beliefs about sickle cell disease that exist in contemporary Ghana.

Lay Beliefs about SCD in Ghana

In the previous section, an in-depth view of the Ghanaian social culture and religion was given and the possible implications for care for children living with SCD were outlined. In this section, discussions will focus on available information on lay beliefs about SCD in Ghana, whilst making analogies where possible with findings from other countries. These discussions are intended to derive explanations or understanding as to the possible effects of these beliefs on parental (fathers) care for SCD.

As a prelude to discussing this topic, let us briefly reflect on the social construction of illness to further understand lay beliefs about SCD. Below is a quotation from Berger and Luckmann, (1967) cited in Mishler et al. (1981:141) to set the tone for the discussion.

“While it is possible to say that man has nature, it is more significant to say that man constructs his own nature, or more simply that man produces himself....It is important to emphasise that the relationship between man, the producer, and the social world, his product, is and remains a dialectical one. That is man (not of course in isolation but in his collectivities) and his social world interact with each other”.

It can be inferred from this quotation that peoples’ perception of what they describe as illness or health, and even the possibility that the illness can be cured or is incurable, are very much dependent on cultural values, social norms and culturally shared rules of interpretation. This constructivist approach to social reality, which is reported to

locate social meanings in the active interpretive work of human actors, is very much in contrast to the biomedical concept of disease causation (Mishler, 1981). These contrasting perceptions may possibly underlie the social construction of beliefs about SCD, many of which mainstream biomedical practice may find unacceptable and unbelievable.

Despite any reservations from a biomedical perspective, social scientists have considered lay perspectives on a wide range of chronic illnesses and have contributed immensely to the general understanding of the illness experience through disease conditions such as leprosy (Mishler, 1981); rheumatoid arthritis (Bury, 1982); Parkinson's Disease (Pinder, 1992; Nijhof, 1995); cancer (Mathiesen and Stam, 1995); hypertension (Thorogood, 1990, Morgan, 1996) and diabetes (Pierce and Armstrong, 1996; Rajaram, 1997; Helman, 2000).

Their main areas of concern have been in the wider context of beliefs about causes of disease, real and anticipated stigmatisation, biographical disruptions, uncertainty and fear and the diversity of coping attempts aimed at renegotiating their identities and reconstructing their 'self' (Helman, 1985; Corbin and Strauss, 1988; Charmaz, 1991,1994; Mathiesen and Stam, 1995). According to Helman, the cause of illness has been variously reported to lie with the patient, the natural world, the social world or the supernatural world.

Social commentators have also described the variety of lay concepts of what constitute health, illness and chronic illness and related these to their implication for care both at home and in the hospital setting (Morgan et al. 1985; Calnan, 1987; Radley, 1993; Freund and McGuire, 1995; Ahmad, 2000). In their accounts, the

Parson's model of the sick role is given detailed attention whilst arguing out the incongruence of the model to chronic illnesses. Parsons (1951) explains the sick role as following certain codes of conduct. These codes of conduct in a four-fold manner confer on the sick certain rights and responsibilities. Parsons further explains the need for the legitimatisation of the sick role, provision of care until well and most importantly a desire by the sick to get well thereby necessitating a need to seek expert help. In their critique, the authors cited suggest the unsuitability of the Parsonian model to chronic illness.

In another aspect, the literature describes what are perceived as folk illnesses and their symbolic meanings to a group. According to Rubel (1977), folk illnesses are syndromes from which a particular group claim to suffer and for which their culture provides an aetiology, a diagnosis, preventive measures and regimens of healing. He further explains that the folk illnesses possess a moral, social, or psychological symbolic meaning to those who suffer from them and in some cases link such suffering to supernatural causes.

In some cases, the expression of physical symptoms of the illness is believed to imply the past or present involvement of the sufferer in social conflicts such as misunderstandings with family, friends and neighbours (Rubel, 1977; Good, 1977; Ebin, 1982; Krause, 1989; Barnett et al. 1999; Cornwall, 2001).

Sontag (1978) and Radley (1993) portray a similar dimension of illness as metaphors in the minds of a group. By metaphors, serious diseases for which causes cannot be ascertained, and for which treatment seemed difficult, are historically constructed to

represent all that is unnatural and socially or morally wrong with society. Typical examples are tuberculosis, syphilis, cancer and more recently HIV/AIDS. All these diseases are biomedically chronic. Whilst some can be cured over a prolonged duration of treatment, others can only receive palliative treatment. The assignment of these metaphors by social groups seem to be linked to any condition for which 'quick fix' cures do not exist or are impossible, persist in presentation of symptoms and probably affects the physical appearance of the sufferer.

Other important contributions to the social analysis of chronic illness have been the discussions on biographical disruptions (Bury, 1982), social death (Lawton, 2003), loss of self and reconstruction of identities (Goffman, 1959; Charmaz, 1983, 1991, 1994; Hyden, 1997; William, 1984, and Ciambone, 2001).

In their varied expositions, these authors narrate how chronic illness disrupts one's life leading to a reconstruction of meanings into the illness, social isolation and the harnessing of available resources to renegotiate a new self of probable low self esteem, restricted life style and lack of opportunity to validate oneself through meaningful association with others or a stable sense of coherence and order. These concepts may explain some of the parental reactions to the diagnosis of SCD among newborns in Ghana.

Further accounts of lay perspectives on sickle cell disease in affluent societies such as the UK have emphasized the attempts of the young people and their carers to negotiate their lives with a view to asserting their 'normalcy' as much as possible

(Atkin and Ahmad, 2001). However, in the UK the rise in the awareness of sickle cell has been after the emergence of technical medical knowledge about the disease, whereas in Ghana, there has been a tradition of centuries that has tried to explain repetitive pain and so called 'repetitive death' (Nzewi, 2001). Furthermore, managing a life-long chronic illness like SCD and its correlation with the psychological well being of the patients has been reported to be burdensome on those affected coupled with the problem of stigmatisation (Bamisaye et al., 1974, Goffman, 1984).

Pain, a common and recurrent feature of SCD, is another important feature of chronic illness that has culture-specific expression and meaning. Depending on the perceived cause of the pain, treatment for cure is sought accordingly. This may range from self expiation (enduring pain because it is a divine punishment to have SCD), orthodox treatment, self imposed penitence (fasting and prayer), use of home remedies, through to exorcism, where it is believed that interpersonal malevolence such as witchcraft or sorcery is thought to be the cause of chronic pain (Engel, 1950; Ebin, 1982; Wolffers, 1998; Helman, 2000; Cornwall, 2001, Leonard, 2002). In Ghanaian culture, there are reports of sorcery, witchcraft, divination and exorcism as causes and cure for socially or medically unexplained diseases.

The role of religion as a coping mechanism in the lay concept of health and illness has also been documented. It is perceived as a great source of comfort and strength when one is confronted with the challenges of life. It is reported to give meaning to hardships, suffering and tragedy as well as a great pillar to lean on for courage and hope (Henley and Scott, 1999). For some religious persons, the power of God is what

sustains them and helps them to move on in life despite very trying situations. Everything that happens is because it is God's will upon their lives (fatalism). Other writers on religion and health have indicated a clear activist/fatalist dichotomy as being influenced by peoples' social classes, in that those in the middle class are more likely to chose an activist stance compared to those in the lower class who assume a fatalist position (RUHBC, 1989). Other authors on this concept, such as Mullen (1994), argue that the position of fatalism is not total or passive and that individuals are continually involved in cooperating with God to improve health.

Other forms of coping with chronic illness by patients and family have also been reported. These range from embracing the medical explanation to their illness through patient and family education, personal/social constructions of own meanings to the disease, confrontation, acceptance, complaining, avoidance, use of social services, normalisation, social withdrawal, family support, depression and the use of available resources at their disposal such as power, money, self-esteem, values, education, beliefs and marital status (Shapiro, 1983; Jessop, et al. 1988; Gray, 1994, Hill, 1994; Midence and Elander, 1994; Olley and Olley, 1997; Anionwu and Atkin, 2001; Meijer et. al, 2002).

On the other hand, a number of studies among black families living with SCD in the USA have suggested that families may attempt to keep SCD diagnosis a secret. France-Dawson (1986), Linde (1972) and Travis (1976) have reported that SCD is shrouded in myths and misunderstandings that lead Black families to react to its diagnosis with denial, secrecy and feelings of stigma. These tendencies to denial,

secrecy and feelings of stigma may possibly be attributed to the African cultural concept of marriage, child bearing and caring outlined in the previous section.

Again, these reactions may be deeply rooted in the social construction of normality and abnormality as implied by Berger and Luckmann, (1967) and the fact that people with chronic disease (disability) are seen as culturally dependent. Katbamna et al, (2000), in a study of perceptions of disability and care-giving relationships in South Asian communities in the UK, reported similar findings. Furthermore, Finch and Groves (1983) and Read (2000) comment that mothers are perpetually engaged in the emotional work of mediating the discrimination of society against their children. They describe the diverse sacrifices that mothers make in the labour of love to protect their offspring and keep the family from stigmatisation.

The findings within the U.S and the U.K on lay concepts of disease are reportedly similar to lay concepts of SCD in other African countries and Ghana. For instance, in a study by Nzewi (2001) on recurrent reincarnation and sickle cell disease carried out in Nigeria, findings showed that communities in Southwestern Nigeria (*Igboland*) identified and described SCD children as malevolent *ogbanje* (revenge driven, chronically ill and engaged in repeated cycles of birth, death and reincarnation). It is believed that such children are sent to the couple through repeated birth and infant death to frustrate them as a revenge for some evil committed by them or their extended families. Consequently, families will give such children death related names (*onwu*-death, *onwudike*-death is powerful, *onwukwe*-if death permits or *omwuchekwa*-death please wait) in the belief that through such names death will be deterred.

This finding is also true for Ghana where families who suffer recurrent deaths of infants give death-related names (*sumina*-rubbish or incinerator, *asaaseasa*-no more ground to bury you) to such children to deter recurrent death (Sarpong, 1974). Other ways of addressing this problem were by bestowing scarifications on the child's body or sometimes through amputation of a finger in the belief that such marks enslave them spiritually and again prevent recurrent infant death (Sarpong, 1974, Stevenson and Edelstein, 1982). Most often because these beliefs are attributable to the spirit world, families spend fortunes moving from spiritualists to native doctors seeking remedy. Underpinning these actions are the beliefs that through them the disease can be cured (Tremayne, 2001; Richards, 2002).

As the communities described and ascribed signs and symptoms to malevolent *ogbanje* – by Nigerians, or *kosanbra* (going and coming) in Ghana, biomedical science ascribed them to sickle cell disease. Documented reports on lay beliefs about SCD in Ghana seem scanty. However, in a study by Dennis-Antwi et al. (1995) assessing the educational needs of health workers and consumers prior to newborn screening in Ghana, a group of patients who were interviewed in a focus group attributed the cause of SCD to spiritual and demonic forces. This finding accords with that of Nzewi (2001). The parents also believed that SCD patients should not eat groundnut, okro, fats and oils because these precipitate onset of acute complications. This is supported by Hill's (1994) findings among mothers of low-income families who believed that symptoms of SCD were diet-related. Other beliefs and attitudes reported by these patients reflected a negative self-image, hopelessness and frustration. Expressions made include:

“ I am the most unfortunate and hopeless person”. “I will not live long”. “I am going to be poor because I cannot do any hard work”. “I am a financial drain on my family”. “I have no faith in the future of this child because I have had one before and he died”.

These statements strongly reflect some of the lay concepts or beliefs about SCD in Ghana that have strong implications for child care. Other speculations about SCD are that SCD patients die young and therefore need not aspire for higher education, and that patients need not learn a trade because they will soon die anyway (Dennis-Antwi, 1994-2003, *unpublished observations*).

Reports in the literature on societal quest for cure for chronic illnesses have ranged from use of metaphysical means, orthodox medicines and home remedies or folk/traditional medicines. These home remedies include the use of salt- sugar-solutions and enema for diarrhoeas in rural Zimbabwe, Nicaragua and Saudi Arabia (de Zoysa et al, 1984; Rasheed, 1993; Hudelson, 1993), ayurvedic kinds of medicine for a ‘snakebite’ or a ‘fracture’ in Sri Lanka (Wolffers, 1988) and ‘*ya-tom or ya-mor*’ in rural Thailand (Nilmanat and Street, 2004). These reports strongly suggest however, that culture is not created in a vacuum.

Moreover, the expectation of a short life for SCD patients is related to socio-economic circumstances, level of services, and societal expectations. Disability rights authors in the UK and North America have constructed more positive self-images for people living with chronic illnesses (Oliver, 1996). Meanwhile Serjeant and Serjeant (2001) recount several Jamaican patients aged over 70.

All these factors bring into focus again the socially constructed nature of the illness of SCD and the possibility of a new social reconstruction (Burr, 2003; Gallefoss, 2004) towards a positive outlook of productive living in the face of an effective programme of SCD management.

As part of this study on the social meanings of a child with SCD, efforts have been made to fully examine the variety of social and lay concepts about SCD that exist in Ghana. Reported reactions of denial, secrecy and feelings of stigma in the Ghanaian context have been explored and much of the information generated will boost the scanty documented body of knowledge that exist in Ghana on social conceptions of SCD and what their significances are to childcare and clinical practice.

Living as a Parent of a Child with SCD in the UK, USA and Ghana

So far the researcher has outlined aspects of SCD management that have great bearing on care for children with the condition. She has discussed the medical literature, health care provision, social, cultural and religious aspects of the disease drawing comparisons where data is available between Ghana, other parts of Africa and the developed world. The lay concepts of SCD, the concept of social constructionism and their implications for care have also been outlined. In this section the focus is on another essential aspect of SCD management and that is how parents live with SCD. Again, lessons from the UK, USA and Ghana have been incorporated into the discussion.

Generally, living as a parent of a child with SCD involves the active engagement of the social, cultural and material resources at his or her disposal to address the challenges of the illness (Beresford, 1996). Parents are often confronted with physical, emotional and financial difficulties in their day-to-day experiences with SCD. The variety of emotions reported in the literature includes frustration, guilt, anxiety, helplessness, loneliness, isolation and resentment (Anionwu and Atkin, 2001). They therefore adopt creative, dynamic and variable strategies in dealing with the disease with variable degrees of success (Frydenberg, 1997; Anionwu and Atkin, 2001). These experiences are reported to be exerted throughout the entire life of the child with resultant long-term effects on the parents such as uncertainty, stress and marital conflicts sometimes leading to divorce (Atkin, 1992; Hill, 1994; Midence and Elander, 1994; Ahmad and Atkin, 1996). Hill (1994: 91) vividly describes the U.S. experience by mothers through her statement:

“ The stress that mothers experienced in care-giving was heightened by the lack of home care advice but also by uncertainty over when and why pain crises emerged, whether pain could be managed at home or required hospital care and the suffering and threat of disability or death wrought by health crises”.

This finding is congruent with those of Telfair et al. (1994); Atkin and Ahmad, (1999) and Atkin et al. (2000) who note that parents are generally concerned about the future of the SCD child in terms of the condition getting worse, early death, future social integration, employment and most of all the availability and use of appropriate support services for their children.

In the U.K, the review of the literature showed that parental living with SCD was not very different from that of the U.S. It is argued that parents' ability to cope with SCD is not an individual gift but, as earlier alluded to, is greatly influenced by the material

resources, family support, knowledge of the condition and services available (Atkin and Ahmad, 1999; Chamba and Ahmad, 2000). They further noted that such parents applied their religious beliefs in living and coping with the disease, and only partially embraced the medical model of coping as also reported by Hill (1994). They adopted their own lay concepts of the disease and used coping mechanisms and strategies based on critical observation and experience to deal with the day-to-day challenges that arose.

On the subject of services for families affected by SCD, the above advocates of better care in the UK have expressed their dissatisfaction with existing government policies and provision of care for such people with special needs (Midence and Elander, 1994; Hill, 1994; Atkin and Ahmad, 1999; Anionwu and Atkin, 2001). They acknowledge however that positive strides have been made in providing some services for such families.

A study of these services included antenatal screening for SCD, prenatal diagnosis (Katz Rothman, 1994; Etorre, 2002), counselling, clinical care, parents' education on SCD and community/social support such as housing, financial and health care support. These services, though not optimal in the view of the advocates, do provide considerable support to parents in coping with SCD. Antenatal, neonatal screening and prenatal diagnosis (Dyson, 1999; Streetly, 2000) potentially offer the pregnant woman or nursing mother the opportunity to assess her sickle cell status, know that of her child and to make an informed decision about the baby or foetus.

Counselling services support and facilitate decision-making abilities of parents whilst technologically advanced medical facilities (comprehensive centres) available for

clinical care ensure quality and prompt care for patients when they are ill. Parents' education programmes provide and enhance their knowledge and health care maintenance skills in understanding the medical model of the disease and how to manage the patient at home. Support services, though reportedly inadequate for the minority ethnic communities, offer some relief in providing housing and financial support for families who are affected and who cannot afford care. The establishment of support groups by communities and health care professionals have provided a source of social support and camaraderie for families to relate to each other and share experiences.

In reflecting on the Ghanaian situation, it has already been established that 2% of all babies born have a form of SCD. Clinical management of patients is basic and does not reflect recent advances in treatment. Special health care services for persons with special needs such as SCD patients are virtually non-existent save the facilities available in Accra, Kumasi and more recently Sunyani and Koforidua.

There are no welfare systems for providing housing facilities for disadvantaged families. Health care financing is extremely limited and low-income families affected by SCD are highly disadvantaged and reportedly prone to disintegration. Furthermore, the researcher described the Ghanaian social, cultural and religious family life and clearly outlined their implications for care of affected children.

All these vivid descriptions create a mental picture of what it will be like to live as a parent of a child with SCD in Ghana. The argument by Atkin and Ahmad (1999) and Anthony et al. (2003) that parents' ability to cope with SCD is not an individual gift

but one greatly influenced rather by the material resources, family support, knowledge of the condition and services available, if applied to the Ghanaian context, tends to emphasize the under-privileged situation most parents living with children with SCD in Ghana find themselves in. Anionwu and Atkin, (2001) suggest that parents are thought to go through on the one hand, nor the degree of success that their creative, dynamic and variable strategies in dealing with the disease yields on the other (Frydenberg, 1997; Anionwu and Atkin, 2001).

These questions and speculations can best be answered through an in-depth investigation looking at all the factors outlined above. This social study into SCD addressed these questions with a particular focus on fathers.

Caring for a Child with Disability or Chronic Illness: Social Impact on Fathers of Children with SCD in Ghana

In this last section of the chapter, the researcher reviews SCD as a disability and chronic illness, as well as aspects of caring for such children. The researcher also explores the social implications of their care with reference to fathers. The anticipation is that exploring these will open up useful avenues of enquiry for making sense of their impact on affected families.

Disability is commonly defined as the social reaction to the presence of physical and mental impairment, whilst a chronic illness is one characterized by periods of steady state and severe illness (Ahmad, 2000). SCD is a haemoglobinopathy characterized as a chronic illness, associated with serious complications that could affect the physical

and mental well-being of the affected person. SCD can influence the daily living of patients, undermining their abilities and expectations for daily living when compared with their peers (Anionwu and Atkin, 2001). Political tensions exist in the classification of SCD as a disability because of the inclination of affected families to perceive discrimination and disadvantage in the provision of services and opportunities to those affected. These experiences of discrimination are comparable to those experienced by other disabled people and introduce the argument that SCD can usefully be conceptualised as one example of a chronic illness attracting social stigma, but amenable to challenge by adopting a disability rights perspective (Oliver, 1996; Stuart 1996).

Caring for a child with disability and chronic illness is described as a daunting task to which most parents (carers) have adopted socially constructed and partially medically appropriate coping strategies to deal with (Atkin, 1992; Hill, 1994; Midence and Elander, 1994; Ahmad and Atkin, 1996; Treadwell and Gil, 1994; Barbarin, 1999; Anionwu and Atkin, 2001). In the previous section, what it means to live as parent of a SCD child was explored, and findings suggested the level of physical, emotional and psychological stress they experience in their day-to-day care of the children throughout their lifetime.

Caring for children with SCD in the context of North America and the UK reportedly involves daily routines of administering prophylactic medications, laborious task of coaxing the child to eat as they will often refuse food, visiting the child's school to explain the condition, seeking support services, providing nursing care when the child is unwell and making frequent visits to the health care facility (Hill, 1994). Sometimes

this is complicated by the need for the parents to look for someone else to care for the child whilst they go to work, and lack of child care may require that they absent themselves from work during the period of ill-health. It is at this point that the services of the extended family become useful and beneficial for those who are fortunate to be living with a mother, aunt, cousin etc (Midence and Elander, 1994).

Below is a quotation from Hill, (1994: 93) that summarizes one aspect of helplessness and frustration that caring for a child with SCD involves. A mother states that:

‘The worst thing is just watching the pain, because I feel like I should be able to do something, and I get to the point where I can’t do anything except watch her hurt and suffer. That is the hardest part for me: my hands being tied, period, is hard’.

An examination of the literature on psychosocial aspects of SCD shows that it is an area that has recently been opened up to study (Hill, 1994; Midence and Elander, 1994; Smith and Wethers, 1994; Treadwell and Gil, 1994; Kelleher & Hillier, 1996; Anionwu and Atkin, 2001). Findings of such studies have shown that patients are prone to developing depression, dissatisfaction with body image, social isolation, low self esteem, anxiety, decreased participation in normal activities of daily living and poor peer and family relationships, though they are highly dependent on their family (Treadwell and Gil, 1994).

Social implications of parenting a child with SCD have been characterised as involving frustration, guilt, anxiety, helplessness, loneliness, isolation and resentment (Anionwu and Atkin, 2001). A positive outcome of such experiences is reported to be highly influenced by the coping strategies the parents are able to adopt in dealing with

the stress of care. Coping resources such as money, power, education, knowledge about the disease and marital stability have been reported to reduce stress (Hill, 1994).

Most of the studies have documented the social impact of the disease on mothers. These studies have shown that the child's condition affects the mother's mental and physical health when compared to fathers of chronically ill or mothers of healthy children (Jessop, et al. 1988). The absence of emotional support, the presence of other stressful factors, the impact of the condition on the family and the woman's physical health were also predictive of psychiatric symptoms among mothers (Midence and Elander, 1994). These findings have been very useful in addressing some of the problems associated with health care provisions in the developed countries. The exact roles that fathers play in the care of SCD children or children with chronic conditions, and how they also cope with having such children, have generally not been documented. This is most likely to be because the groups studied have had to raise these children as mothers alone without fathers (Hill, 1994). For various reasons, mothers rather than fathers bear the responsibility of caring for children with chronic conditions (Midence and Elander, 1994).

Socio-cultural aspects in defining gender roles in marriage have been known to be a crucial factor in this pattern (Brown, 1996; Salm and Falola, 2002). This is supported by Katbamna et al. (2002). They note that men's normative primary role is restricted to the procurement of material resources and therefore they are not expected to play a major role in caring for their sick and disabled relatives. This may be a strong societal influencing factor that perhaps explains the seemingly limited involvement of fathers in care-giving whilst strengthening the concept of reproductive genetics and its

tendency towards the promotion of the cultural ideology of motherhood (Hill, 1994), social discrimination of disability (Katbamna et al. 2001) and the social imposition of limits and restraints on the gendered body of the woman as the carrier of the pregnancy (Katz Rothman, 1994; Etorre, 2002). However, where they have played supportive roles, fathers have been reported by Midence and Elander (1994) to have a great influence on the personality, values and attitudes of their children. However, it is not known what meanings fathers attach to their role in the care of their children with SCD and the significance of those roles in improving SCD management.

A focus on Ghana indicates that little if any research has been conducted on the area of chronic illnesses and their social and psychological implications for the affected families. The role of men in caring for the sick has not been documented. Presently, little if any is known about fathers' reaction to chronic illness. Ten years of observation and interaction with parents and patients affected by SCD in Ghana by the author suggests that mothers are the ones who are greatly affected by the presence of the disease because they are the ones often seen by health professionals with the affected children. The fathers, by contrast, are rarely the ones who bring children for medical attention at clinics.

Moreover, SCD management programmes in Ghana are limited and have not considered the social context within which families learn to cope with the disease and its implications for effective care in much detail. As stated earlier, most families have little organised support from the Government (Dennis-Antwi, 1997). It may even be possible that men play integral roles in the care of their children with chronic illnesses and that gender roles constructed by society, as well as lack of organised systems of

care for such children, are contributory factors to their apparent lack of involvement reported in much of the existing literature. An investigation into possible strategies for the health and social sector (in Ghana) in addressing the support needs of people living with sickle cell disease in particular and chronic diseases in general may serve to explain this observation.

Conclusions

An examination of the literature on SCD in the course of this chapter has shown that the disease is a serious genetic disorder affecting people of various ethnic origins world wide. An assessment of the prevalence of SCD indicated that a large proportion of affected people live in sub-Saharan Africa. African countries, in view of their social, economic and political environment, lack the statistics on the disease burden of SCD, perpetuating a situation where it is not considered as a disease of public health importance.

Comprehensive care of SCD patients should include patient and parent information, genetic counselling, social services, infection prevention, nutrition education, psychotherapy, a diverse range of medical and surgical specialist care as well as specialised nursing care (Okpala et al. 2002). Ghana is very much limited in the provision of such holistic care.

Recent advances in SCD treatment have given hope for the cure of SCD. About 100 people worldwide have benefited from these treatments, some of which are very expensive. However, Africa in general and Ghana in particular, with their high concentration of sickle cell patients stand little immediate chance of benefiting from

these advances as they lack the financial, economic and scientific resources to bring any of these therapies to the doorstep of affected families.

An outline of the context of Ghanaian social, cultural and religious family life suggests that children are a 'must have' in most Ghanaian marriages and therefore the birth of a newborn is greatly treasured. However the expectation is that the child is a normal healthy one. This expectation does not make a SCD child very welcome due to the disruption of family expectations and the implications for their ongoing care.

For various reasons, mothers rather than fathers bear the responsibility for caring for children with chronic conditions (Midence and Elander, 1994). Socio-cultural aspects in defining gender roles in marriage have been known to be a crucial factor in this pattern (Brown, 1996; Salm and Falola, 2002). Where they have played supportive roles, fathers have been reported by Midence and Elander (1994) to have a great influence on the personality, values and attitudes of their children. However, it is not known if fathers' role in the care of the children with SCD makes any significant impact on themselves and in SCD management.

The literature reports a limited range of lay conceptions surrounding the birth of a child with sickle cell disease in Ghana. The worst of these is that these children are an economic drain and will rob families of all their riches through medical bills. Perhaps it is due to these longstanding conceptions of what SCD may mean, that it is asserted that fathers are more likely to withdraw from their family responsibilities. In some cases the presence of sickle cell children has led to separation or divorce, though in the UK context its occurrence has been reported as rare (Midence et al, 1992). A

review of the literature on lay concepts about SCD has also brought into focus the social construction of illness and efforts that are made by the society within their social construct to address these problems. These perceptions are crucial in informing health professionals in the best ways to support people and families living with SCD.

The social and emotional aspects of SCD is an area that has recently been studied with respect to ethnicity (Anionwu and Atkin, 2001), culture (Kelleher & Hillier, 1996) low income groups (Hill, 1994), health care maintenance (Smith and Wethers, 1994) coping strategies among carers especially mothers (Midence and Elander, 1994; Hill, 1994) and how it had to be politicised in order to derive attention from the powers that be within developed countries such as the UK and USA (Anionwu and Atkin, 2001). Most of these studies have been carried out among affected groups living in the developed world and for whom the social dynamics contrast with those of Africa in general, and Ghana in particular.

The argument by Atkin and Ahmad (1999) that parents' ability to cope with SCD is not an individual gift but rather one greatly influenced by the material resources, family support, knowledge of the condition and services available draws attention to the under-privileged situation most parents living with children with SCD in Ghana find themselves in. In the UK context, Midence and Elander (1994) have noted that chronic illness is almost always a financial liability and an important factor in the overall impact of the disease on the family. This is corroborated by the personal observations of the researcher in Ghana.

From the outside it might appear that parents are likely to exhibit emotional stress such as frustration, guilt, anxiety, helplessness, loneliness, isolation and resentment upon the birth of a child with SCD. However, this study seeks to place these assumptions to one side and to listen to the accounts that fathers give of this experience. An investigation into the experiences of Ghanaian fathers will increase the existing body of knowledge and inform better care for affected families.

What the existing literature fails to highlight concerning the social impact of SCD are the underlying factors that influence limited male involvement in the care of the sick and their effect on optimal care. Assumptions made direct to gendered division of labour, the biological positioning of mothers, the burden of SCD, to lack of health and social services. Fathers are portrayed as in Hill's (1994) book as having tendencies to walk away from children with SCD whilst the mothers bear the full responsibilities for care. These assumptions exclude the possible disposition of couples to be incompatible with one another for a variety of reasons in the course of a relationship thereby negatively influencing a cohesive existence that facilitates male involvement in child care.

Other assumptions portrayed in the literature include the apparent effects of caring for the chronically-ill child on the mother without recourse to what the socio-cultural disposition of men dictates. That is, though it is perceived as natural for women to show emotions in the face of challenges, men are culturally trained to stand up to challenges and hide their feelings and emotions.

These are some of the issues and questions that underlie the social aspects of being a father of a child with chronic illness such as SCD. Perhaps more social investigations into the social and cultural features associated with black families might be expected to provide in-depth understanding into the effects of SCD in Ghana and Africa and assist in accommodating chronic illness (Le Pontois, 1975).

Until more is known or acknowledged about the way that socio-cultural factors affect fathers' adaptation to chronic illness, the scope for improvements in the provision of effective emotional and social support services towards families living with SCD will be significantly restricted.

This present study to investigate the social meanings of a child with sickle cell disease and the reaction of, and social impact on fathers in Ghana will consider the extent to which these themes from the literature are reflected in the accounts given by Ghanaian fathers of SCD management in Ghana and consider the implications of these accounts for social policy.

In the next chapter, the researcher presents the strategy and methods used in investigating these issues and questions.

CHAPTER THREE:

STRATEGY AND METHODS

Chapter Two explored the health care services for SCD patients within Africa (especially Ghana) and compared these services, as well as the effects of these services on the survival of patients, with the situation in Europe and North America. The social and emotional aspects of SCD disease were also discussed, including the manner in which parents adapt their caring strategies in looking after such chronically-ill persons, and the meanings fathers give to having a child with SCD in the particular socio-cultural context of Ghana.

In this chapter, a critical examination of the positivist and subjectivist approaches to social research is given, providing supporting evidence for the suitability of an approach based on understandings, meanings and motives in investigating the present research. The limitations of the approach have also been acknowledged and steps to counter these limitations in the research described to ensure the analytical generalisability of findings. To achieve these objectives, the chapter has been set out in five main sections: 1) the overall methodological approach to this study, 2) the sampling strategy and sampling process, 3) the study sample, 4) the method of data analysis, validity, reliability and generalisability, and 5) ethics procedures and limitations to the study.

Overall Methodological Approach to this Study

This study investigated the social meanings of a child with SCD and the perspectives and reactions of fathers in Ghana. The social meanings a group attach to a child with a chronic disease such as SCD, meanings that have been socially constructed over generations, calls for methods that allow for close interactions with the group being studied rather than the reliance on observable 'factual' phenomena from a positivist standpoint.

Furthermore, a review of academic and professional literature investigating either sickle cell itself, such as that of Hill (1994), and Midence and Elander (1994), or related areas such as racism in a medical setting, such as Porter (1993), suggest a need to move beyond a positivist approach. These qualitative approaches allowed the researchers to understand the social world from the point of view of the group being studied whilst also acknowledging the wider structural influences helping to produce such experiences. This is referred to as adaptive theory (Layder, 1998). Accordingly, this study adopted a similar strategy within a modified ethnographic and realist framework. It was ethnographic in the sense that it allowed for an in-depth understanding of the social interactions that define fathers' perceptions and relationships with SCD children. The study also strongly considered the need to remain open minded in order to discover the elements making up the markers and the tools fathers of children with SCD mobilise in their interactions with their social world (Baszanger and Dodier, 1997: 9).

The study drew on a realist framework by linking the identified perceptions and reactions of fathers to the wider social, cultural, and material structures of the Ghanaian society that generate such relationships (Hammersley, 1992; New, 1995). As a modified ethnographic approach, the level of participation by the researcher was not equated to a direct participant observer, but rather consisted of one who has had a long-term experiential and professional association with parents of children with SCD in the specific linguistic and geographical area of Ghana studied. However, the researcher did not typically adopt a single role throughout the study. There were situations when she needed to offer some educational and counselling support to all the fathers and to mothers, thereby making her a researcher-participant. The researcher speaks the languages of Twi and Ga relevant to the participants, and has in the recent past been involved in some depth in participating in supporting families with children living with SCD, and so is well-placed to generate the type of cultural description required to make sense of the social context of SCD in Ghana.

Ethnography is relevant for this study because the research question seeks to understand the perspectives of the subjects within a broader cultural context (early 21st century Ghana), and needs to be sensitive to the influences of language (Ga, Twi) to customs and to religion. It is a holistic strategy that is capable of taking account of situational responses to questions (for example, the prevailing expected role of men in child rearing in rural Ghana).

To position the choice of the methodological approach to the study and the actual method used, a comparison between two main epistemological approaches to research has been outlined below, namely: 1) subjectivism, especially the traditions of ethnography and social constructionism, and 2) positivism

Subjectivist Approaches

The subjectivist research traditions that influenced the development of this study, included ethnography, social constructionism, and (through Layder's adaptive theory), critical realism. Ethnography as part of the subjectivist position has its roots in anthropology and represents the direct study of particular human actions within a wider context as a means to understanding the culture of a social group (Bogdan and Taylor, 1975; Jorgensen, 1989; Dyson and Brown, 2005). Similarly in his explanation, Van Maanen (1982: 103-104) observed that:

“The result of ethnographic inquiry is cultural description....a description of the sort that can emerge only from a lengthy period of intimate study in a given social setting. It calls for the language spoken in that setting, first-hand participation in some of the activities that take place there and most critically a deep reliance on intensive work with few informants drawn from the setting”.

In a related position, social constructionism is a multidisciplinary approach to understanding human action, which holds that human understanding of the world is historically and culturally determined at a point in time. In other words, social phenomena, and the meanings attributed to them, are characterised by continual and constant construction and reconstruction through social interactions (Bryman, 2001; Burr, 2003). This places an onus on the researcher to be reflexive about the impact of her identity and motives in generating the data.

One further epistemological position that was of relevance to this study is that of critical realism. Naïve realism is a commitment to the view that there is an external reality that is separate from the scientist's description of it, and that the natural and social sciences can, and should, apply the same kinds of approach to the collection of

data and to explanation of that data (Bryman, 2001). In contrast critical realism is defined by Bhaskar, (1989:2) as:

“A specific form of realism whose manifesto is to recognise the reality of the natural order and the events and discourses of the social world” and holds that ‘We will only be able to understand and so change the social world if we identify the structures at work that generate those events and discourses’.

This suggests that there may be structural circumstances contributing to the generation of the reaction of fathers to a child with SCD, including socio-economic factors, as well as relations of gender, and social attitudes to chronic illness.

The description of these positions (ethnography, social constructionism and critical realism) tend to suggest that in an ethnographic inquiry, the cultural descriptions about a social group that the researcher accumulates over time is as a result of the continual construction and reconstruction of social meanings of that particular group. These explanations are congruent with the qualitative research strategy. However, to the critical realist, there are underlying factors to the social reality that we see, construct and reconstruct over time; and that to understand these occurrences, we must identify these underlying factors. Therefore the critical realist does more than identify the internal and external constructs. There is a commitment to delve into the generation of these constructs to address whatever the issue may be. A commitment to work to change the underlying factors generating the social experiences of fathers of children with SCD would be seen by critical realism as a corollary of that approach.

Furthermore, according to Bryman (2001), a qualitative research strategy is one that stresses words rather than quantities in collection and analysis of data. A qualitative strategy adopts an interpretive approach to studying the social world and is often associated with the epistemological position of subjectivism. It is concerned with the

subjective, empathic understanding of human action (Von Wright, 1971; Bryman, 2001). Bryman (2001) further describes it as a strategy that seeks to use an inductive approach to determining the relationship that exists between theory and research with strong emphasis on the derivation of new theories.

A qualitative strategy focuses on aspects of individual interpretation of the social world in which they find themselves in and acknowledges the fact that this social world is not constant but changes over time in response to the individual's construction of the world. Similarly, Miles and Huberman (1994) describe a qualitative strategy as one concerned about individual actions rather than behaviour.

According to them, these actions carry with them intentions and meanings and lead to consequences. As proponents of a qualitative strategy, Miles and Huberman further describe its strengths to include a focus on naturally occurring, ordinary events in natural settings, thereby making it possible to see what real life is through the generation of complex and vivid data that is capable of having a strong impact on the reader. It provides data typically collected over a sustained period of time and makes it powerful studying social processes. It also goes beyond snapshots of 'what' and 'how many' to 'how' and 'why' things happen. In support of these strengths, Van Maanen, (1977) also mentions that it places emphasis on peoples' lived experiences and locates the meanings people place on processes, events and structures in their lives, connecting these meanings to the social world around them.

Positivist Approaches

By contrast, positivism is a means of studying the social world using the natural science approach based on principles, procedures and ethos. Often, it includes a deductive move towards determining the relationship that exists between a theory and

research (Bryman, 2001). Positivism is an epistemological consideration adopting a position that leans strongly more on structured research strategies generating more quantifiable data. This empirical data is then regarded as an objective reflection of the real world, thereby constituting what is considered as acceptable knowledge (Bryman, 2001: 11-12). This position claims the research is devoid of personal values, meanings and moral judgements. It conceives the existence of the real world as an external construct independent of what the researcher or the researched thinks – so-called ‘mind independence’ (Cuff et al, 1990).

Comparing Positivism and Subjectivism

Positivist approaches based on methods such as surveys could generate data describing the magnitude of the problem of adverse reaction of a father to a child with SCD, and possibly reasons for certain actions, but will not be able to capture the meanings and values the group give to their particular actions, and hence, for example, whether or not the fathers themselves conceive their reaction as a social problem.. Thus critics of positivism, such as Pawson (1989), argue that it is not possible to obtain direct and unbiased observations of the world since we do not all construct our social worlds within the same frames of reference.

Peters et al. (1986) argue, in assessing the prevalence of social phenomena with reference to the issue of child abuse, that it is possible to have accurate data over time as researchers determine more consistent definitions and the application of the right methods. Taylor (1992: 24-25) however, criticises these views by noting that

“The researcher’s views as to what does and does not constitute child abuse and the ways in which the research is constructed and administered can have important effects on what is discovered...”

The positivist conception of science focuses on factual phenomena and excludes value or moral judgements”.

This implies that there is more to what seems factual or observable, and that to have the true meaning of an issue there is the need to delve into what appears hidden or not easily seen.

Pawson (1989), another strong critic of positivism, points out that people, unlike scientific objects, attach meanings to their actions and that these meanings are a result of discrete values and intangible structures which mediate between what is in the world (a child with SCD) and how it is perceived by members of a group in society (their fathers). He further noted that problems with *imposition* and *correspondence* cannot be ruled out in quantitative studies and will therefore affect what exactly is being measured. The concept of imposition recognises that a researcher conducting a study does not passively stand back and record what is going on but rather that she actively moulds what emerges as data. The researcher tends to structure the questions and the scope of replies in a way that imposes their ideas and sometimes their values on the data collection process. Bateson (1984) supports this point by observing that asking a research question asserts more about the social world than it asks. For example, it could be argued that by focussing on fathers and children with SCD the researcher is implicitly asserting that children with SCD are somehow different and in need of special support, and that it is a problem for society if fathers do not commit themselves to playing an active part in that support.

The problem of correspondence revolves around the respondents' understanding of the questions asked. Pawson (1989) argues that the responses given to questions posed by researchers may not necessarily be the respondents' own interpretation of the

question. One cannot take for granted a correspondence and consistency between questions asked and replies given by respondents because the answer the respondent will give may mean a different thing. However, Pawson recognises that his statement does not necessarily imply the outward rejection of all existing statistical data but rather calls for the use of methods that reduce more obvious sources of error. He further asserted that though the error of imposition may be unavoidable, the good researcher needs to make allowance for it through what he calls the use of *external and internal concepts*.

By these terms, Pawson (1989) described external concepts to be the institutional practices and interactions in the social world whilst internal concepts represent the individual's perception of things, values, opinions or thought processes. He noted that use of positivist methods to measure internal concepts result in inconsistent and unreliable data due to the potential for individuals to give a variety of interpretations. This argument strengthens his earlier assertion for the choice of the right method or epistemology that allows right from the outset, the measurement of concepts that are acceptable and considered consistent within that framework. Since what the fathers themselves understand by a child with SCD and the place of that child in their lives involves primarily internal constructs, this suggests that an interpretive framework for the current study is more suitable than a positivist one.

Pawson's (1989) arguments and strong preference for the subjectivist epistemology in the description of internal concepts (constructs) do not necessarily imply that interpretive, qualitative approaches are free from criticisms. The key criticisms of the

interpretive approach have been in the areas of subjectivity, lack of replicability, lack of transparency, and problems with reliability and validity.

Qualitative strategies, according to their critics, may be too reliant on the unsystematic views of the researchers as well as the development of close ties with the people studied (Bryman, 1994; Bryman, 2001,). Qualitative approaches have also been criticised for lack of replicability, due to the uniqueness of each person studied and the fact that the interviews are highly unstructured, with the researcher being the main instrument of data collection. In the conduct of this study, the researcher reflects on these criticisms, and describes initiatives taken to limit their effects on the findings that emerged (Silverman, 1998; Bryman, 2001; Bryman, 1994; Denscombe, 2002).

The Actual Study Method and Fieldwork

The whole study was conducted on the basis of a comprehensive field work that was carried out in Kumasi, Ghana between April 2004 - May, 2005 and April, 2006 using the sickle cell clinic (SCC) at Okomfo Anokye Teaching Hospital (KATH) as the study setting. This setting was familiar to the researcher in that it was one in which she had worked for over ten years as the Education and Counselling Coordinator of the SCD project. She been instrumental in establishing the parent and patient education component of the project and therefore felt well integrated into its operations. She therefore used her network and links with the professionals and families to recruit her participants. This meant that the researcher needed to be aware that her identity as perceived by the respondents was likely to be one of representing officialdom, in the form of a health professional.

Subsequently, the researcher set out to systematically carry out in-depth interviews with respondents in the following order i) a pilot focus group of nine mothers; ii) a pilot focus group of 7 specialist health workers in the SCC; iii) a pilot of 7 fathers; iv) further interviews with 23 fathers as part of the main study and finally; v) a single interview with a father who had absconded from his family. A summary of data collected is given in Table 2.

The initial pilot interviews (i-iii) were carried out with the purpose of interviewing the mothers and health workers to gather insightful data into the lay concepts of SCD and to provide a possible source of referral to fathers of children with SCD. The interviewing of the pilot of fathers was to test the topic guide for its validity and reliability and to create the opportunity for making necessary modifications to the guide before the main interviews. Details of modifications have been outlined under the fourth section of this chapter. Moreover, this topic guide was developed through the review of literature, advice from supervisors, senior professional colleagues and families living with SCD.

The local language of ‘Twi’, which is widely spoken, was used as the medium of communication for the interviews (Appendix One: English/Twi topic guide). The researcher is very fluent in this language and therefore did not require the mediation of a translator. However, in conducting the interviews in the local language of Twi, the researcher was aware of the possibility that concepts particular to one language and cultural context would not necessarily directly translate to another context. The researcher is thus aware of the nuances of the local language. As a health professional trained through the medium of English, she is also conversant in technical medical

terms, about for example, patterns of genetic inheritance. Nonetheless, there remain some occasions where there is scope for a non-correspondence between local Twi lay concepts and Western medical knowledge. One such example is the phrase used by the fathers that the blood of the mother and the father “do not meet” or “do not agree”. In technical terms this might be thought to refer to rhesus incompatibility, but in fact the fathers used such terminology in relation to sickle cell disease. In this way it seems that they had partially apprehended the technical medical knowledge about sickle cell disease, but had incorporated it into their world view in such a way as retain a connectedness with their culturally specific view of the world.

A further example concerns the notion of chronicity. There is the possibility that the Twi concept of “a condition that refuses to go” might relate to a chronic illness such as diabetes or HIV/AIDS. By contrast, infections such as malaria might usually be expected to come and eventually pass. However, because sickle cell is characterised by bouts of repeated infections, for the father who has not been exposed to technical medical explanations of sickle cell, this poses an explanatory problem, and a metaphysical explanation may come into play. However, without an understanding that SCD underlies the recurrent bouts of infections, the fathers would not necessarily conceptualise the repeated illnesses as constituting chronic disease.

Thus as with malevolent Ogbanje (which seems to refer to a range of recurrent childhood deaths, not only those that are SCD-specific deaths), it is not simply the case that there is a lay concept that maps precisely onto a technical medical concept, but that there is some overlap without complete correspondence. To this extent caution is required in interpreting concepts between Twi and English”.

All verbal communications were tape-recorded in order to provide a record of actual occurrences in their actual sequence, as Sacks (1984) puts it, and labelled using a predetermined pseudonym such as F1, F2, F3 etc. and stored safely. Full translation and transcription of the interviews were carried out in English by the researcher and field notes were kept using a special notebook assigned to the study.

Respondents were asked for informed consent prior to each interview. The consent of participants was reconfirmed on tape during each interview, and further consent was sought for the researcher to take notes during the course of the interviews. This request was accepted by all the fathers in the sample and therefore notes were taken as and when necessary. The field notes made included dates, times, place of interview, background information on respondents and statements made by respondents that were believed to be exceptionally informative. Also noted were observations on respondents' reactions to questions and how they recounted their lived experiences with SCD. For instance, in a particular interview with a father (Father 7) who lost his 'dear' son with SCD, there was a point in time during the interview where he broke down in tears as he recounted the last few days prior to the death of his son and what he felt he should have done for that child prior to his death. He said:

“Mine is the experience of losing my son (long pause). I will like to share this with you though it is difficult for me. It hurts me so much and I seem not to be able to forgive myself. What hurts me most was that I have borne his sickness for all his life but at the time of death when he needed me most I did not meet his needs because I felt tired. If I knew that was his last request, I would have done anything for him. When I remember this scene I can't help than cry (shakes head, pauses and begins in a laboured manner). “That day, the painful crisis he went through that time was too much to bear. I remember the night before his death I could not sleep. The boy was in so much pain. He requested that I go out and buy a local pain ointment to come and massage him. I told him to bear with the pain and that as soon as it was daybreak, I would go and get it for him. In the course of the night, I woke up to go and check on him. I touched him and I realised he was gone. He died in hospital. This was a painful experience for me (father cries for about 5mins)”

Notes made on this interview, reflected the pain expressed by the father and the meaning he attached to his inability to meet his son's 'last' request. It offered a contemplative sobering experience for the researcher and a feeling of understanding for fathers of children with SCD.

Table 2: Sources of Data Collected

Sources of Data Collected		
Source	Number	Reason
Focus Group with 9 mothers	1	To help with the definition of the research problem, to help frame the interview topic guide and to gain access to a sample of fathers
Focus Group with 7 health professionals associated with the SCD screening programme	1	To help with the definition of the research problem, to help frame the interview topic guide and to more formally document the lay beliefs and informal community strategies for SCD management known to the researcher by virtue of her involvement in the SCD screening programme
Pilot interviews with fathers	7	To evaluate the topic guide and amend the topic guide in the light of experience
Main interview with fathers	23	The main body of data collection
Fieldwork	3	2004: Participated in monthly Sickle Cell Support meeting to enable researcher recruit sample of mothers, health workers and fathers for the pilot research. 2005: Participated in monthly Sickle Cell Support meeting to enable researcher to recruit sample of fathers for the main study 2006: As a form of reciprocity for those fathers who had contributed and the beginning of actions to improve SCD management taken in the light of findings <u>and</u> as part of strategy of "searching for disconfirming evidence" (Glaser and Strauss, 1967). It was also to track down an absconding father as none of the fathers in the main sample had not, in fact, absconded
Interview with a father identified as an absconder	1	"Searching for disconfirming evidence" (Glaser and Strauss, 1967)
Fieldwork diary	1	To capture contextual data, to improve the audit trail, to document the researcher effect (how fathers reacted to the researcher) in order to reflect researcher reflexivity.

The Sampling Strategy and the Process of Sampling

The sample comprised up to 31 self-selected or recommended fathers. The self-selection method was similar to that used in a study by Lupton et al (1995). In her study, participants were recruited by means of posters displayed at selected health clinics. However, in this research, fathers were recruited through self nomination, or by nomination through their wives or partners who were members of a support group closely affiliated to a project screening babies at birth for SCD in Ghana (NSSCD). This is an international collaborative research project started in 1993 in Kumasi, the second largest city of Ghana.

Where necessary, the spirit of dimensional sampling (Cohen and Manion, 1989) and of sampling for diversity (Glaser and Strauss, 1967) were employed to introduce diversity and ensure that emerging theories were fully explored. Diversity was crucial in this study in view of its small-scale nature (31 fathers) and the drive to ensure theoretical saturation (Glaser and Strauss, 1967) by capturing a wide range of SCD related life experiences of people with diverse backgrounds rather than just focusing on people with specific typical backgrounds for attaining statistical generalisation. So in this study, respondents were sampled on the basis of such factors as socio-economic background (e.g. middle class, low-class), profession (e.g. Minister of God, farmer, teacher, driver), marital status (e.g. divorced, single with an SCD child, new and young father, separated from mother of SCD child, aged father of a mature SCD son and experience with SCD, political immigrant etc). Other people interviewed were a group of nine mothers who later acted as gatekeepers to gaining access to their husbands/partners and seven specialist health workers who participated in separate

focus group discussions (FGDs) to provide an insight into the subject under study during the pilot phase of the study.

This sampling strategy meant that those who were less integrated into the local support group, and those where the mother or partner did not give permission to approach the father were not represented in the sample. However, the proposed methods of approach seemed the only ones possible to generate an adequate sample of fathers of children with SCD for this present study. The implications of this strategy however have been discussed under the section on limitations to the study.

The Sampling Process

In the study of such a sensitive subject coupled with the social stigma attached to the disease (Dennis-Antwi et al. 1995), it was necessary to recruit people who were willing to be interviewed. Hence, 8 fathers were selected through self-selection (Lupton et al, 1995) with the remaining 23 through gate-keeping with mothers of children with SCD, combined with dimensional sampling for diversity in occupation socio-economic background, marriage status and age. The recruitment procedure duly followed was outlined in the sections on sampling strategy and fieldwork described earlier on in this chapter.

The interviewees were mainly husbands, partners, absconded or divorced husbands of mothers of SCD children actively involved in a support group closely affiliated to a project screening babies at birth for SCD in Kumasi. The mothers played the role of gatekeepers (Whyte, 1981; Lee, 1993) and used their positions as wives/partners to grant, deny or mediate access to their husbands or partners.

Of those fathers who were self-selected, they came of their own accord to be interviewed. Access to them was gained through the support group meeting. By their selection, the researcher attended some of the monthly support group meetings having gained an earlier permission from the executive committee of the association (Table 2). At the meeting, she was granted the opportunity to interact with members and to explain the purpose of her research and its possible benefit to SCD management in Ghana. For her pilot interviews she requested ten mothers of SCD who fitted the criteria for recruitment to join her in a FGD. The invitation yielded about 25 mothers who were later screened through further questioning to eliminate those whose husbands had travelled out of the country or are in-country but lived very far away from the study setting and could not be contacted easily within the pilot period. This reduced the number to a total of 14 mothers. Five of these had children who needed to see the doctor for an afternoon appointment and therefore could not join the FGD. This brought the number further down to 9 and they formed the focus for the interview after which the contacts for their husbands or partners were collected for access. Meanwhile, 4 fathers (F4-F7) approached the researcher as self selected respondents for the interview. The researcher noted their contact details, and they were later contacted and interviewed for the pilot. Three fathers (F1-F3) were accessed through their gate-keeper wives whilst the remaining contacts were rolled over to be added to the list for the main study. The 7 specialist health workers were accessed through the SCC. The researcher had been part of this clinic and therefore used her network and links to recruit these professionals. The likely effect of such familiarity with the respondents has been discussed under reflexivity and limitations.

This brings to a total of 7 fathers and 9 mothers and 7 specialist health workers for the pilot.

In the main study, a similar approach of attending the support group meeting was used to get contact addresses to about 30 fathers. In this instance, after the introductory remarks, the researcher outlined the criteria for recruiting respondents and requested that those who met the criteria wait behind at the end of meeting for further interaction. Mothers who were willing to invite their husbands/partners who fitted the criteria for recruitment were to wait too. Three self selected fathers were willing to be interviewed that same day and therefore the researcher conducted the interviews as such. The recruitment procedure was repeated in a subsequent meeting (Table 2).

Generally, personal details of the self-selected fathers were recorded as well as the contact addresses volunteered by the mothers. With 30 contact addresses and the six contacts 'rolled over' from the pilot, the researcher made 28 contacts via phone and eight by physical visits. None of those contacted in person declined to be interviewed once they had understood the purpose of the study. However, of the telephone contacts, 22 were willing to grant the researcher interviews, 2 could not be reached and 4 indicated some reluctance to be interviewed by suggesting schedule times that were highly dependent on their availability in Kumasi at a later date. They said this was because they had travelled to other parts of the country for work, were not sure of a return date, and that they would telephone to fix appointments. In the end, none of these four made further contact. Out of the 22 enthusiastic fathers, 15 were readily contacted and interviewed based on their availability at that point in time. The remaining seven were later contacted on phone by the researcher, and carefully

informed of the need to exclude them from the interview since the sample size was up to the expected number, and they were not readily accessible. She detected their disappointments and volunteered to meet them if they so desired to hold informal discussions on their child and SCD. Two fathers subsequently took advantage of this offer. A total of 23 fathers were therefore interviewed for the main study.

Evidence that emerged during the pilot focus group with the mothers was that some fathers abscond or divorce their wives because of SCD. The main study therefore sought to determine the extent to which this assertion was true. However, findings in the study showed that none of the fathers interviewed had denied paternity of the SCD child or absconded. A majority (22) out of the total of 30 were still married to the mothers of their SCD children and only 3 fathers were divorced from their SCD related marriages. Of these 3, one indicated that SCD was a contributory factor but not the main cause to his divorce whilst the rest explained that it was due to marital incompatibility rather than SCD. Even in their situation, all three were still interested in their SCD children, and expressed the view that they could do better for their children if their marriage had survived. Moreover, 3 fathers were not married to the mothers of SCD children when the pregnancy leading to their birth occurred. Of these only one had decided he would not marry the partner though he had performed the knocking rites. This was on the pretext of a 25 percent probability that they could have another or more children with SCD. The other two had married other women but their decision to marry was not based on the birth of an SCD child but rather a relationship gone cold. The assertion by the mothers interviewed could not be verified by the study, possibly because (1) the perception of abandonment is actually something of a myth, perhaps a result of mothers' frustrations that, whilst not actually

being abandoned, they receive comparatively little support; (2) the sample of fathers accessed through the NSSCD project had the potential of having a collection of respondents who were empathic to the course of SCD because of their exposure to informed wives or partners which have had a positive impact on their attitude to their children and therefore they have not felt the need to abscond; or (3) fathers who were likely to have absconded would not make any contact at all with their partners and therefore such mothers would not have their contact address to enable them act as gatekeepers for the research, hence their probable lack of inclusion in the research.

To find answers to this seeming lack of evidence, the researcher later revisited the NSSCD and the support group in Kumasi. This was to interact with them as a form of reciprocity and to search for disconfirming evidence on absconding fathers. On that particular day - April 6th 2006 - a total of 265 parents and adult patients attended the support group meeting. Out of this number, only 11 mothers were not currently married to the fathers of their SCD children. Six out of the 11 reported that the fathers were not providing any form of support in the care of the children. The contacts for these men were sought and further interviews conducted with the gatekeeper mothers. This resulted in the identification of three eligible absconding fathers - fathers who had provided neither financial nor hands-on support for the child for more than two years. Of these three, the researcher made efforts to contact them by phone and personal home visits. Two of them lived in communities very far from Kumasi and whilst the remaining one lived outside Kumasi as well but about 40 km away. He was finally located and interviewed after much initial reluctance and suspicion that the researcher was representing social work officialdom and was there to seek justice.

After much persuasion and convincing, and he agreed to the interview and became the thirty-first respondent to the overall study.

The Study Sample: Socio-demographic characteristics of respondents

A total of thirty-one fathers were interviewed. Tables 3 and 4 provide a pen-portrait and occupational profile of the fathers for your study.

Table Three: Pen Portrait of the Sample of Fathers Interviewed

F1	Is a 34 year old father of 2 boys, married to the mother of his children. The youngest with SCD-SS died at age 2 years. He is an orthodox Christian of the Methodist tradition and a low-income clerical officer in the public service. F1 lives with his family in a rented room in the city. He was accessed through gate-keeping.
F2	Is 42 years old, a father of 2 boys and a girl and married to the mother of his children. He lost the 2 nd child who is SCD-SC when he was 14 months. F2 is a Christian of the Pentecostal charismatic type and a small-scale low-income farmer. He lives in a nearby community to the city with his family in a rented room. He was accessed through gate-keeping
F3	Is a 29 years old unmarried father of 1 son who is SCD-SS. F3 still courting the mother of the son. Though they live separately he is in close contact with the mother and child. He is an orthodox Christian of the Presbyterian tradition and works as a part-time bartender and is a student as well. He was accessed through gate-keeping.
F4	Is a 50 year old father of 3 boys and 2 girls and married to the mother of his children. A girl and a boy being SCD-SS. F4 is a low-income Christian Evangelist of the Apostolic faith who lives in a rural community with his family in an official house. He was accessed through self-select sampling.
F5	Is a 52 year old father of 2 boys and 2 girls, married to the mother of his children. He is an orthodox Christian of the Catholic tradition and a teacher. His first son who was SCD-SS died when he was about 12 years old leaving 3. F5 lives in the city with his family in a rented flat. He was accessed through self-select sampling.
F6	Is a 48 year old low income farmer who is a known SCD-SS. He is married to the mother of his 4 children: 3 boys and a girl being SCD-SS. F6 is a Pentecostal-charismatic Christian of the Apostolic faith who lives in a rural community outside the city in a rented room. He was accessed through self-select sampling.
F7	Is a 54 year old father of 2 boys and a girl, 2 of whom have SCD-SS with the eldest boy dead. He is married to the mother of his children and is a middle-income public servant. He is an orthodox Christian of the Methodist tradition and lives in the city in an officially provided house. He was accessed through self-select sampling.
F8	Is a 41 year old father of 3, married to the mother of their children being 2boys and one girl. The girl is the eldest and has SCD-SS. F8 is a orthodox Christian of Catholic denomination. He is a middle-income trader involved in exports and imports and lives in the city in his own house with his wife and children. He was accessed through self-select sampling
F9	Is 49 years with 4 children and still married to their mother: 3 boys and 1girl. The eldest son has SCD-Sβ ⁰ thalassaemia. F8 is a Christian of the Pentecostal-Charismatic type; a timber merchant who owns his own house and lives in the city with his wife and children. He was accessed through self-select sampling.
F10	Is a 43 year old father, married to the mother of his 4 children, 3 boys and a girl. The youngest who is a boy has SCD-SS. He is a self-employed carpenter living in a rented room with his family in the city. He is a Christian of the 7 th Day Adventist denomination. He was accessed through gate-keeping.
F11	Is 37 years old, married to the mother of his 2 children, the first of whom has SCD-SS. He is a

	sales attendant at a shoe shop and lives in a rented room with his family. F11 is a Moslem and lives in the city. He was accessed through gate-keeping.
F12	Is 49 years with 3 children all of whom are boys; the youngest having SCD-SS. F12 has been through 3 relationships. His first marriage resulted in an SCD-SS child who died at age 18 months. In his second relationship which was more of co-habitation, he had two boys, both of whom live with his (F12) mother in a separate house in the city. He is currently married to the mother of his 3 rd son. F12 is a cab driver, a Christian of the Pentecostal-Charismatic type and lives in a rented house with his current family also in the city. He was accessed through gate-keeping.
F13	Is 43 years, married to the mother of his 5 children; 4 boys and a girl with the 3 rd son having SCD-SS. He is an orthodox Christian of the Presbyterian denomination. He is a vegetable farmer and lives with his family in a rural community outside but near the city. They live in their own landcrete house. He was accessed through self-selection.
F14	Is a 50 year old father of 3, comprising 2 girls and a boy from two marriages. He is currently married to his 2 nd wife, the 1 st child of this woman being SCD-SS. F14 is an orthodox Christian of the Methodist denomination. He is a cocoa farmer who lives in a far away community with his wife whilst their children live with relations in a rural community near the city for easy access to health care and reliable education. He sees his children monthly. He was accessed through gate-keeping
F15	Is 44 years old Sierra Leonean, married to a Ghanaian mother of his 4 children two of whom have SCD-SS. He is a self-employed building blocks maker residing in the city in a friend's house with his family. He is a Christian belonging to the Deeper Life Faith. He immigrated to Ghana during the civil war in his country. He was accessed through gate-keeping.
F16	Is 37 years, married with 3 children, all girls. His first child is SCD-SS and was had with a different woman whom he did not marry. F16 is a Catholic Christian who lives in a rented flat with his new wife and their 2 daughters. The SCD child lives with her own mother. He is a banker and was accessed through gate-keeping.
F17	Is a 56 year old teacher, married to the mother of his 3 boys and a girl, the last of the boys being SCD-SS. He is a Catholic Christian living with his family in a rented house in a rural community outside the city. He was accessed through self-selection.
F18	Is 36 years old with 2 sons, married to the mother of his 2 nd son who is SCD-SS. He is a Presbyterian and a senior clerk with a public company. He lives with his family in a rented room including the first son whose mother died earlier. He was accessed through gate-keeping.
F19	Is 44 years is old, married to the mother of his 2 daughters and expecting a 3 rd child. The 1 st child has SCD-SS. He is a Minister of God belonging to the Presbyterian faith. He lives in the city with his family in official house but putting up a place of his own. He was accessed through gate-keeping.
F20	Is a 41year old father of 3 boys and 3 girls, a divorcee of the mother of the SCD-SS girl child and re-married to another. He lives with all the children in a rented premise in a rural community near the city whilst the SCD child lives with her mother. He is a senior stockman in a private poultry farm and a Catholic by faith. He was accessed through gate-keeping.
F21	Is 65 years old, married to the mother of his 5 children, 2 of whom died previously from SCD. The last son is also SCD-SS and alive. He is a Catholic by faith and a photographer by profession. He lives with his family in their own house. He was accessed through gate-keeping.
F22	Is 70 years and a father of 16 children, 3 of whom have SCD-SS with 2 dead, one just recently. He had 4 wives but has divorced 3 and is currently living with one, the mother of his eldest now 36 years old and youngest sons with SCD-SS. He used to be a building contractor and lived with all his children when they were young. He is Catholic by faith and now lives with the wife and some of the children in their own house in the city. He was accessed through gate-keeping.
F23	Is 49 years old and a father of 3 boys and 3 girls, one of whom has SCD-SS (boy). He is a divorcee of the mother of his first 4 children, the SCD-SS inclusive and remarried to his wife of 2 children. He lives with his new family in a rented premise in the city. F23 is a driver and a Methodist by faith. He was accessed through gate-keeping.
F24	Is 35 by age, married to his wife of 2 boys both with SCD-SS, the youngest dying recently. He is a mason and a Catholic by faith living in his own house with his family in the city. He travels a lot on work related trips and sees the family monthly. He was accessed through self selection.
F25	Is 38 years old, married to the mother of his 3 girls and a boy. One of the girls has SCD but he does not know her genotype. F25 is a food crop farmer, a Pentecostal-charismatic by Christian faith and living with his family in a rural community near the city. He was accessed through self

	selection.
F26	Is 28 years with an only child who has SCD. He could not tell the genotype of the child as the child had been newly diagnosed. He had the child during courtship and plans to marry the mother of the child. F26 is a Catholic, a teacher in basic school who lives in a rented room in the city and visits his son routinely. He was accessed through gate-keeping.
F27	Is a 31 year old father, married to the mother of his 2 daughters, the last of whom has been newly diagnosed to have SCD. F27 is a Christian but does not belong to any denomination. He is a petty trader living in a rented room with his family in the city. He was accessed through gate-keeping.
F28	Is 41 years and a father of 3 girls from 2 marriages. He has divorced the mother of 2 and married a new wife whose first child has SCD. F28 is a Christian of the 7 th day Adventist faith. He is an accountant at a bank and living temporarily alone in a rented flat in the city. He was accessed through gate-keeping.
F29	Is 40 years with an only child who has SCD-SC and married to the child's mother. He is a lab-tech and a Presbyterian by faith. He lives in the city in a rented room with his young family. He was accessed through gate-keeping.
F30	Is 48 years old father married to his wife of 2 girls and a boy who has SCD-SS. F30 is a teacher and a Methodist by Christian faith and lives with his family in the city. He was accessed through gate-keeping.
F31	Is 40 years old and a father of 2 children, a divorcee of the mother of the children and married to another. F31 is a cash crop farmer and a Christian by faith. He lives with his new wife in a rural community where his children also live with their mother. He was accessed through gate-keeping.

Table Four: Occupational Profile of Fathers

F1	Is a low-income clerical officer in the public service
F2	Is a small-scale low-income farmer.
F3	Is a part-time bartender and a student as well.
F4	Is a low-income Christian Evangelist
F5	Is a teacher in a basic public school
F6	Is a low income farmer
F7	Is a middle-income public servant
F8	Is a middle-income trader
F9	Is a timber merchant
F10	Is a self-employed carpenter
F11	Is a sales attendant at a shoe shop
F12	Is a cab driver
F13	Is a vegetable farmer
F14	Is a cocoa farmer
F15	Is a self-employed building blocks maker
F16	Is a banker
F17	Is a teacher
F18	Is a senior clerk with a public company.
F19	Is a Minister of God
F20	Is a senior stockman in a private poultry farm
F21	Is a photographer
F22	Is a building contractor
F23	Is a driver
F24	Is a mason
F25	Is a food crop farmer
F26	Is a teacher in basic school
F27	Is a petty trader
F28	Is an accountant at a bank
F29	Is a laboratory technician
F30	Is a teacher in a basic school
F31	Is a cash crop farmer

For the mothers, three (3) were traders, four (4) were unemployed (previously having been traders but suspended in order to care for SCD child), one was a seamstress and one a nursing assistant. These data suggest that a majority of the respondents fell broadly within the low socio-economic group, suggesting that financial constraints could conceivably be a limiting factor in the care of their SCD children.

Below is a table depicting the living status of the children belonging to the fathers and mothers:

Table Five: Living Status of Children of Fathers and Mothers in the Study

Description	Total Number of Children	Number Alive	Number dead	Reason for Death
FATHERS (F)				
F1	2	1(with SCD)	1	SCD
F2	3	2	1	SCD
F3	1	1	-	-
F4	5	5 (2 have SCD)	-	-
F5	4	3	1	SCD
F6	4	4 (1 with SCD)	-	-
F7	3	2 (1 with SCD)	1	SCD
F8	3	3(1 st child-girl with SCD)	-	-
F9	4	4 (1 st child-boy with SCD)	-	-
F10	4	4 (last boy with SCD)	-	-
F11	1	1(boy with SCD)	-	-
F12	3	(3 last boy with SCD)	-	-
F13	5	5(3 rd boy with SCD)	-	-
F14	3	3(1 st girl of 2 nd marriage)	-	-
F15	4	4 (3 rd -girl and last – boy with SCD)	-	-
F16	3	3 (1 st girl with SCD)	-	-
F17	4	4 (last –boy with SCD)	-	-
F18	2	2(last-boy with SCD)	-	-
F19	2	2(1 st –girl with SCD)	-	-
F20	6	6(5 th with SCD)	-	-
F21	5	3 (last boy with SCD)	2 died at 8 and 4 years	SCD
F22	16	14 (1 st with SCD)	2(girl and boy)	SCD
F23	6	6 (3 rd girl with SCD)	-	-
F24	2	1 (boy)	1 (boy)	SCD
F25	4	4(1-girl with SCD)	-	-

Description	Total Number of Children	Number Alive	Number dead	Reason for Death
F26	1	1(1 st child with SCD)	-	-
F27	2	2(2 nd -girl with SCD)	-	-
F28	3	3(last- girl with SCD)	-	-
F29	1	1(1 st child boy -SCD)	-	-
F30	3	3 (3 rd child boy-SCD)	-	-
F31	2	2	-	-
MOTHERS (M1)				
M1	5	4 (1 with SCD)	1	SCD
M2	3	3 (1 with SCD)	-	-
M3	1	1 (with SCD)	-	-
M4	3	3 (1 with SCD)	-	-
M5	3	3 (1 with SCD)	-	-
M6	1	1 (1 with SCD)	-	-
M7	1	1(with SCD)	-	-
M8	2	2 (1 with SCD)	-	-
M9	2	2(1 with SCD)	-	-

It could be inferred from the table that eight out of the 31 fathers interviewed had had the experience of losing one or more children from SCD. These fathers represent around one third of those interviewed. It was envisaged from the outset by the researcher that the meanings fathers attach to this loss would provide a rich insight into the emotional aspects of SCD, and the extent to which their experiences differ from those who have not had that experience.

Overall, the researcher acknowledged the biases that the sampling strategy introduced into the study. It meant that those who were less integrated into the local support group, and in situations where the mother or partner did not feel like participating as a gatekeeper, meant that the fathers of their children could not be accessed. Moreover, fathers and mothers who happened not to attend meetings on the days of recruitment were automatically excluded.

However, the methods of approach adopted seemed the only ones possible to generate an adequate sample of fathers of children with SCD for this present study.

Method of Data Analysis: Validity, Reliability and Generalisability

In the previous section, the researcher outlined the method of sampling and the process followed in generating the sample for the study. Having gathered the data, it became imperative to adopt a method of analysis that would effectively bring out the social reality of respondents in relation to the research questions. It is generally recognised that there are no straightforward rules that guide the analysis of qualitative data when compared with quantitative data (Bryman, 2001: 387). However, there are approaches that could be employed. Analysis of this research data was conducted through thematic analysis.

According to Denscombe, (1998: 220), Miles and Huberman, (1994: 10), and Maykut and Morehouse, (1994), there are a number of advantages attributed to qualitative analysis of data such as that of thematic analysis. The researcher drew on these advantages in order to produce data that reflected events in their naturally occurring settings. Some of the advantages they describe include the fact that it is locally grounded in reality. Secondly, it provides richness, holism and detail to the data. Another advantage is its tolerance of ambiguity and contradictions that reflect the social reality being studied as well as the fact that it offers prospects of explaining the data in alternatively valid ways. With such strengths to her advantage, the researcher analysed data generated through the identification of patterns, processes, common ideas and differences (Miles and Huberman, 1994) as they emerged from the transcribed text and also the use of these as a basis for generating themes or interconnections relevant to the categories of data at hand.

Presentation of Data and Analysis

On the development of transcripts, each tape recorded interview was played and replayed and the recorded information written out in full and verbatim by the researcher herself. All the transcripts were then compiled to flow according to the main sections of the topic guide (Appendix 1) e.g. courtship and marriage, symbolic value of children etc. and statements of respondents laid out under each section using reference codes other than the respondent's actual name e.g. F1, F2, F3 etc. (see Appendix VI)

As the data emerged, respondents were categorized based on existing theories, the research topic, professional background or any social affiliation relevant to the research (Silverman, 1993: 81, Denscombe, 1998: 211). Words and phrases such as courtship, traditional marriage rites, division of labour, childbearing, "*health is wealth*", "*As for child upbringing, you learn it from others*", "*An illness that is a burden*" etc. were useful in directing the categorisation of data into themes and ultimately into theoretical constructs. These categories were subjected to continuous modification during analysis to improve on earlier versions. Themes were generated from the emerging data to form a total of fourteen themes and three theoretical constructs as outlined in Chapter Four. These were useful for discussing findings and theorising in comparison with relevant literature and professional body of knowledge. Appendix VI presents an example of details of documenting the process of analysis.

Qualitative approaches in view of their subjectivist stance lend themselves to criticisms of lack of reliability, validity, transferability or generalisability. The

researcher describes these in the light of her study and outlines approaches adopted to ensure the trustworthiness of her data.

Reliability

Hammersley, (1992: 67) defines reliability as the '*degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions*'. LeCompte and Goetz (1982) describe two forms of reliability. External reliability is the degree to which a study can be replicated across time. This they noted is very difficult to achieve in qualitative research as it is impossible to 'freeze' a social setting and the circumstances under which the initial study was conducted. They define internal reliability as the degree to which a research team agree to what they see or hear if they are observing the same situation. Reliability debates in social research tend to question the extent to which reliable measures can be produced in the social world as compared to the positivist world. Research focussing on interpretation and meaning recognises that at each encounter a unique account is produced. LeCompte and Goetz (1982) further suggested that to ensure reliability in a qualitative ethnographic research, it is important to adopt a similar social role to the one adopted in the original research.

The pilot served as a model for the main study. It offered the opportunity to pre-test the relevance of the reviewed literature to findings, interview guide, proposed research methods and ethical challenges. On the whole, there were no major setbacks that impeded the implementation of the pilot. However there were lessons learnt that had implications for the main study. For instance, findings of the pilot study informed the review of the interview guide used for the subsequent interview of twenty-four

fathers all contributing to this thesis. The conduct of the main study was modified to reflect the following lessons learned:

Review of literature

The initial review of the body of knowledge for this study did not focus on lay concepts of SCD and their social implications. In the pilot, part of the information generated described the lay knowledge of SCD thereby necessitating the review and inclusion of such literature in the overall thesis. Also included was literature on the concept of the meaning of pre-natal diagnosis and on the gendered division of labour within the Ghanaian socio-cultural context.

Research Diary

In the pilot, the research diary kept a log of the researcher's activities (Bryman, 2001) to support the tape-recorded discussions of such conversations. It focussed on categories such as the date, time, venue and respondent socio-demographic details. However, it did not consider participants' actions and reactions at first hand and any adverse reactions, though it observed the emotional state of the respondents. Moreover, notes were made without necessarily following a rigid routine of recording immediately after each interview, thereby leaving room for the bias of selective memory. To address this gap, the researcher adopted the use of a pre-designed outline in recording field notes immediately after each interview. As part of the interviewing, the level of willingness of fathers to participate and the outcome of the interview were vividly recorded. Six (6) fathers out of the 23 involved in the main study were extremely enthusiastic about the interview whilst the remaining 17 agreed upon asking and showed enthusiasm and cooperation in the course of the discussions. During the pilot seven fathers were interviewed and the data generated included in the

overall analysis and presentation of this thesis thereby adding up to the total of 31 respondents

Interview Guide

A pre-designed open-ended interview guide was used in conducting the interviews during the pilot and the main study. Through the experience gained during the pilot, the researcher saw the need to include certain questions on the guide for the main study.

Some of the questions were “*What is the difference between knocking and marriage rites?*” “*Can you tell me your best experience(s) you have had with SCD and why?*” “*Can you tell the worse experience you have had with SCD and why?*” These were to generate meanings and derive important factors that influence the social reactions of fathers. Others were “*What is your understanding of health and illness? Tell me what you understand by chronic illness? Is SCD one? Explain*”. “*What makes some men bring their children to the hospital whilst others do not? What role does traditional division of labour play in this practice? Is it important to increase paternal involvement in hospital care of their SCD children? Explain? How did some overcome it and what can be done?*” “*How does your child perceive her condition? Does she feel bothered? How does this affect you?*” “*Why do some fathers abscond from their families/child with SCD? What can be done to keep these men interested in their children?*” “*How widespread is the practice of churches requesting testing of blood before marriage? What role can this practice play in social development?*”

Allowing these modifications of the pilot questions ensured that the data gathered in the main study covered the in-depth experiences of respondents. The researcher also maintained the flexibility of including relevant questions as they emerged from previous interviews as outlined above.

In this study, the author adopted a reflexive position as it was not that of a replication study. This she did by means of keeping a research diary and constructing an 'audit trail' which documented the phases of the research processes in an accessible manner to ensure a higher dependability and possible transferability of findings to other contexts (Guba and Lincoln, 1994).

As part of the audit trail, the researcher recorded salient information provided by the respondents in the fieldwork diary and compared that to the recorded messages to ensure consistency in the information given. In the course of the interviews, the researcher also sought for clarifications on ambiguous statements to increase the dependability of responses.

Validity/Transferability/Generalisability

Validity refers to *the extent to which the information generated represent the truth of that being measured*. That is whether the researcher is observing, identifying or measuring what she says she is (Mason, 1996: 24). This takes two forms: internal and external validity. Internal validity measures the extent of congruence between the researcher's observation and the theoretical ideas these observations generate.

This attribute has been observed to be a strength of ethnographic research because of the prolonged participation of the researcher in the social life of the study group (LeCompte and Goetz, 1982; Bryman, 2001). One manner of tackling the issue of internal validity is by returning to a select group of the respondents and asking them to listen to their interviews or read their transcripts for confirmation (respondent

validation, see Reason and Rowan, 1981; Bloor, 1983: 172; Bryman, 2001: 273). However, research focussing on perceptions, motivations and meanings recognises that at each encounter a unique account will be produced. Therefore validity in this research was achieved partly by permitting the fathers to speak freely within their own frame of reference without imposing the researcher's own framework onto their social world, albeit that the researcher is recognised as being a health professional affiliated to the SCD programme. Furthermore, the use of multi-method approach of data collection involving FGDs, in-depth interviews and fieldwork diary also served to enhance the credibility of the data.

External validity, considered as one of the problems of qualitative research, measures *the degree to which findings of this study can be generalised across social settings*, traditionally a challenge for research based on depth interviews, owing to the small size of the sample. To address this problem of transferability, thick description of the meanings fathers attach to producing a child with SCD (Geertz, 1973) were provided. 'Thick' descriptions entail not only a detailed description giving the reader a sense of vicarious presence, but a willingness to link specific occurrences to the broader cultural meanings to which they relate. Furthermore, this body of knowledge will serve as a very good database for other social researchers who might have an interest in studying similar social phenomena in the same context at a different time (Bryman, 2001). Besides, the researcher has vividly communicated the context of research process to the reader, thereby providing a platform for possibly recognising the extent to which the findings may be transferable to other social contexts.

Moreover, in this study, the researcher decided that such an approach to give ‘self recognition effect’ to respondents could alter the data collected as it raises the question of the extent to which the respondents could follow a report written for a sociological audience. Another reason for not attempting to return transcripts had to do with the extent to which the respondents felt the analysis was compatible with their self-image. To address this, the researcher adopted a strategy of confirming and reconfirming aspects of respondents’ responses during the interview process to ensure consistency and affirmation. In addition, the researcher adopted the position of treating all data comprehensively using appropriate tabulations (Silverman, 2001: 236). This resulted in an integrated and precise model that explicitly described meanings as well as offering links of specific occurrences to the broader cultural meanings to which they relate (Mehan, 1979: 21, cited in Silverman 2001: 240).

Reflexivity

According to Bryman (2001: 470), reflexivity has several meanings in the social sciences. Firstly, it may imply the ethnomethodologist’s reference to speech and actions. Secondly, it may mean the social researcher’s need to reflect on the implications of her methods, values, biases and decisions for the knowledge of the social world they generate. A third possible meaning refers to the implications of the researcher as involved in the construction of knowledge through the position she assumes in relation to the observations made and the account transmitted. As the researcher of this study, I am more concerned with the second meaning as it makes reference to the relationship that exists between the researcher and the social world that is being studied. It recognises the influence our values, concepts and norms as

researchers have on the interpretations we give to our findings and questions the objectivity of data.

The previous sections discussing the limitations of qualitative subjectivist methods have explained how the issue of objectivity has been addressed in this research. As a researcher who has had previous exposure to families with sickle cell disease, it is possible that my experiences and my personal values could have positive or negative influences on the outcome of the research. It is therefore wholly impossible to assert that this research study will be value-free and it is therefore important to acknowledge that my experiences could lead to the taking of sides in the interpretation of the data collected.

To support this point, Becker (1967: 239, 247), in his presentation to a group of sociologists, argued that:

“.....To have values or not to have values? When sociologists undertake to study problems that have relevance to the social world we live in they find themselves in a crossfire. Some urge them to be neutral and value free in undertaking research..... I propose that this is not possible... We take sides as our personal and political commitments dictate, use our theoretical and technical resources to avoid distortions that might be introduced into our work, limit our conclusions carefully, recognise the hierarchy of credibility for what it is”.

Based on this statement, the data generated from this study on SCD and fathers in Ghana, and the interpretation given to the data, were carefully made. The researcher took cognisance of the notion of *hierarchy of credibility* (the notion that members of the highest group e.g. government, health professionals, family elders, community leaders have the right to define the way things really are) that arose to explain certain

occurrences or situations in the data interpretation (see also ethical issues and analysis of data).

For instance, since the researcher has been known to respondents as a government health official, her understanding of SCD will be considered high status, and perceived as the privileged one in the hierarchy of credibility. Therefore, in order to understand respondents, the researcher carefully and skilfully facilitated the interviews to persuade them that she would both listen to, and take seriously, views that may be alien to her and which may surprise her. She also ensured that her perceptions to the issues discussed were kept silent even when respondents wanted her opinions in the course of the interviews. Rather, she reciprocated at the end of the session by answering questions asked, by clarifying any misunderstandings of technical medical information, and by sharing her developing views on how social meanings around SCD-related events are constructed.

Ethics Procedures and Limitations to the Study

Having provided an insight into the methodological implications of data analysis, and the steps adopted by the researcher to address issues related to their reliability, validity and transferability to wider social contexts, in this section the researcher further outlines the ethical aspects to her study and the limitations associated with such a study.

Ethical Procedures

The methods used in the study raise some ethical issues in the face of the sensitive nature of the subject being studied. The British Sociological Association (2002, #s 13,

16, 17) argues that “*Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research*”.

In accordance with this statement, the author in the study accorded prime attention to the aspects of intrusion of privacy, accessing respondents, confidentiality and their anonymity. On *intrusion of privacy* she considered the assertion that SCD comes with a potential social stigma that influences most affected families to try to keep the diagnosis as a secret from the general public (France-Dawson, 1986). To address this potential ethical problem, she chose to access fathers through mothers of SCD children who acted as gatekeepers. She gained informed consent from these husbands or partners to interview them.

A sheet explicitly describing the purpose of the research was read to both the mothers and fathers in the local language of *Twi* as a prelude to each interview (see Appendix One-English version with the *Twi* translation written in italics). They were assured that they had the liberty to decline to be interviewed, and that this would not in any way affect their relationship with the researcher - a known focal person in the clinic, and the social support group.

They were also given the option of deciding themselves where to be interviewed and assured that they were at liberty to refuse to answer any questions that they were uncomfortable with. This taped permission was so as not to intimidate and to affect the willingness to participate of a group with a wide range of literacy skills. The choice of language was *Twi* to ensure consistency in the use of methods. They

expressed their consent verbally at the outset of each interview, and the researcher recorded this verbal consent on tape. At the end of the interview, respondents confirmed by speaking their consent on the record at the end of the taped interview, reiterating their permission for the researcher to use the information obtained. Some expressed their consent as follows:

“Because of the love and interest you have for us and our children, it will be ungrateful on my part to refuse you if you need to have some information from me. This is how I can thank you. I have enjoyed this conversation a lot. It has thought me a lot of things”. [F4]

“I agreed because I treasure knowledge.....Knowledge is priceless compared to riches”. [F6]

“Because I wanted to learn from you to benefit my child. And I must say that I have learnt a lot through the questions you asked and the answers I gave. It has made me attentive to certain things I would normally have ignored” [F8]

“We are all humans and humans talk to each other. We cannot hide the fact that my child has a problem so if someone who knows about the problem desires to see you, why should you refuse?” [F20]

These responses make interesting reading and suggest several ways they could have “learned”. (1) An in-depth interview has elements of non-directive counselling (Rogers, 1945) in it, and simply by being a sounding board for people’s views and experiences, the researcher may have enabled them to become more reflective of their own situation and therefore they may have felt they had “learned”. (2) It may be that in the course of the conversation the researcher had cause to explain something technical about SCD or about access to services for SCD and that they had “learned” in this way. These contributions reflect an act of the reciprocity which is commonly held to be part of ethical interviewing (Finch, 1984). (3) They may have looked up to me morally because I was formerly part of the local services and a professional person.

One can however argue further that respondents felt they had a moral obligation towards the researcher to reciprocate by consenting to being interviewed (Oakley, 1990). On the other hand, it can be argued that respondents also felt that they had something to benefit from the study such as knowledge and proper care for their children in the near future. Hence there was a feeling of mutual reciprocity, which suggests the interviews were not experienced as exploitative.

For instance, for those fathers who had never attended support group meetings, the researcher had to explain aspects of SCD to them. Areas of interest to the fathers included children frequently eating foam (pica), inheritance patterns, chronicity, cure for SCD, good nutrition, the parental role in caring, the future benefit of this research to care and management, the average lifespan of SCD patients and the attitudes of health workers. With two of the fathers (F7 and F16), the researcher had to offer emotional support by acknowledging their pain and allowing them to express their grief by giving them a listening ear as they broke down in tears when they recounted their stories concerning the death of a son and marital problems associated with having an SCD child. When they calmed down, the researcher counselled them and suggested the need for them to participate in support group activities so they can interact with people in similar circumstances and share experiences and knowledge in how best to live with SCD, marriage and loss. On the instance of the absconder, the interaction provided him the opportunity to better understand SCD and the need for him to act as a role model in encouraging and building up the ego of his affected son to achieve despite his situation. It also helped him appreciate the supportive role of officialdom rather than its critical and judgemental side. Of those who desired to be interviewed, but could not be, the researcher explained the objective of the study to

them and the need to keep to a limited number for the purpose of the research. She however assured them of her willingness to spend time with any of them who desired to discuss pertinent issues concerning their children and for which they required her counsel. A total of ten fathers and mothers were met with through this avenue at the end of the three association meetings that the researcher attended.

The researcher had a moral obligation to meet the needs of these respondents and perceived it to be a part of the reciprocity that a morally responsible researcher should offer in return for the respondents' participation (Oakley, 1990) in the study. These varying roles also offered invaluable information on the field relationships in the various situations that they were encountered (Gold, 1958; Gans, 1968; Bryman, 2001). For example, the author kept a field diary as recommended by Burgess (1982) and Dyson (1995) to document all such events in order to enhance data analysis.

To do so the researcher developed a template describing the following categories: name and address, age, number of children, children sex and number with SCD, marital status, religion and denomination, ethnicity, occupation, where parents lived and whether the father lived with the children. Other categories of interest in the field diary were notes on how the respondents were accessed and general comments about how the interviews proceeded and the level of enthusiasm shown by the respondents (Appendix V).

Access

The study gained access to the fathers through self selection or through their wives or partners. These wives were in turn accessed through the local support group. Second,

permission to carry out this research was sought by submitting a copy of the research proposal to three main recognised and important bodies including: The Faculty of Health and Life Sciences Human Research Ethics Committee of De Montfort University, the Advisory Committee of the Newborn Screening for SCD Programme in Ghana and the Sickle Cell Disease Association of Ghana-Ashanti Region Branch. All three organizations wrote granting their approval.

Respondents, except the absconding father, did not exhibit any reluctance to share or describe their understanding and experiences with SCD and their affected children once the researcher had explained the basis for their invitation. Rather, they were more than willing to contribute to a body of knowledge that may possibly have a positive influence on social aspects of SCD management.

Most of them were extremely enthusiastic about the interview and saw it as a form of recognition. They reported feeling privileged because the interview gave them the opportunity to be recognised as the fathers of the affected children. Secondly, they had never been asked about how they were coping with care and how they met the day to day needs of their children. Most of the interactions at the SCC had been with the mothers of the children. Thirdly, there had been little research conducted among the affected population, in contrasts to the situation in the USA or UK. In the Ghanaian context, being part of the research accorded a vicarious sense of status to those chosen, much like the Hawthorne Effect that could be argued to have arisen in specific social-historical circumstances where being the focus of research was new. This contrasts with UK research into minority ethnic groups, where such groups may

feel over-researched or exploited by researchers, and are reportedly weary of research that does not lead to any perceived improvement in health or social circumstances.

The willingness of the fathers to be interviewed may be judged by the fact that 18 out of the 30 enthusiastically agreed to be interviewed whilst the remaining 12 agreed upon a clarification of purpose of interview after their wives as gatekeepers had informed them of my interest in interviewing them. The potential benefit of participating in the interviews was the potential of contributing towards better services for their children. The fathers themselves describe their attitude to be interviewed as follows:

“I came because I am interested in my child’s welfare. What ever I can do to help this child I will try to do it. I wanted to gain more knowledge from you” [F1, similar sentiments were expressed by F8, F13, F20, F25, F28].

“If you are pursuing such a study in support of SCD, we have to give you the necessary information to enable you present the facts. This will enable those who read your dissertation to know the situation. May be through that we can have a policy and other countries too can benefit. It can also help in raising funds towards SCD projects”. [F7]

“I believe by so doing we could make life for the SCD child better. May be if others had done what you are doing earlier, there would have been more improvement in the life of our children”. [F12]

“I must say I was surprised when I received your call. I had a feeling that my wife may have called upon you to settle the squabble between us. But I enquired from my daughter about what happened during their last visit to the clinic and she mentioned that they gave my number to you. Because their mother does not know my number and I have strongly decided in my mind that there is no way I will reconcile with a woman who is unfaithful. Right now my son is very hostile to me because of the rift between their mother and me. But I am happy to have talked to you after all”. [F 23]

As a result of the enthusiasm shown, and the expression of fathers to have more of such interactions, which they found very educative, the researcher suggested to the support group to hold a fathers’ forum as a means of interacting with all the fathers of SCD children. This forum was held on May 20th, 2005 and it was a highly successful meeting providing opportunities for parents especially fathers to share experiences

and extend mutual empathy towards each other. A total of 284 fathers attended the session. The major outcome of the meeting was paternal acceptance to increasingly and actively participate in their children's' care as well as regularly attend any sickle cell organized forum. Generally, the fathers felt very happy and privileged to be called for the meeting to discuss their role in childcare.

Another group of respondents who were enthusiastic about participating in the research were the specialist group of health workers who contributed to documenting information on the lay beliefs about SCD. The researcher suggests that similarly, their attitudes were in recognition of a known colleague conducting a research which the team felt was very much relevant to the current challenges to optimal care for SCD patients. They noted that the lay beliefs surrounding SCD affected the optimal uptake of treatment given to patients, and they felt convinced that documenting and publicising findings was an opportunity to contribute towards the de-stigmatisation process in Ghana and Africa.

Confidentiality and Anonymity

All information collected during the research was treated as highly confidential. All field notes and tapes were kept under strict lock and key. The transcripts of recordings were carried out privately by the researcher alone in a room. A list of all the respondents was made separately before interviews and transcriptions began. Also, a pseudonym using numbers e.g. F1 M1 was given to each one of them respectively. These pseudonyms were used for all labelling and references whilst the master list was kept separately and private. Respondents were assured of this and copies of labelling shown to them.

During the pilot, issues relating to access, confidentiality and anonymity had major implications for the main study in that there were likely to be more people willing to be interviewed than the author desired because of their tendency towards reciprocity. Furthermore, it was anticipated that respondents would also desire an opportunity to have time to ask questions about the research or some aspect of the disease that they were unclear about. These anticipated concerns actually came up in the conduct of the main study. As a way of addressing them, the researcher ensured that at the end of each interview, she spent a minimum of thirty minutes to answer respondent questions and give counsel where needed. Some of the questions raised concerned how best to get a specialised research and management centre for SCD, how Ghana could provide some sort of financial waiver for cost of care and how best to integrate fathers in SCD education sessions.

Limitations to the Study

The approach of this research is described as a *modified* ethnographic strategy. Covert research was not possible, since the identity of the researcher as a health professional was already widely known. The pure ethnographic strategy also has a tendency to generate detailed descriptions with no linkages to existing theoretical positions, nor the ability to derive one (Denscombe, 1998). To counter such limitations, the researcher employed an overt position whereby she declared her position and intentions for conducting the research to the fathers and mothers involved in the study and solicited their cooperation for data collection.

Within the overall qualitative framework, the methods of data collection employed included in-depth interviews, focus group discussions (FGDs) and a reflexive fieldwork diary to ensure a higher degree of confidence in findings. The key reasons behind such choices were that interpretivism and qualitative approaches suggest that there are many different meanings that may be constructed around social phenomenon. Thereby the use of a multi-method approach allowed for a searching out of truths, truths that are influenced by changes over time and the sense that a person's own internal concepts change over time and are continually being reconstructed based on emerging experiences. Such outcomes would also acknowledge that, because meaning is constructed in the process of inter-personal encounters, what people say at individual interviews may not be the same as they say in a focus group, nor indeed in an interview with a different interviewer.

The multi-method approach also provided a higher response rate than if the researcher had employed the method of surveys, due to the fact the method relied on personal interactions. Cognisance was taken of the documented limitations associated with these qualitative methods such as likelihood of losing control over proceedings of FGDs, heavy reliance of interviews on verbal behaviour and problems with transcribing interviews.

Practical steps were taken to limit these disadvantages through good note taking and use of skills in group facilitation. For instance, respondents' questions and desire to know more about SCD and the topic under investigation were steered towards the end of the interviews to allow for more interaction and keep the interviews in focus.

Another dimension to the limitations to this study is the categories of fathers and mothers who could not be interviewed. These include 1) fathers of children who were not closely associated with the support group 2) fathers and mothers who, though affiliated to the group, did not opt to be interviewed, 3) fathers who attended private medical services and therefore had little contact with the general experiences of SCD among lower socio-economic groups, 4) parents who were not available on the days of recruitment of sample, 5) fathers who could not be interviewed, though contacted, due to their non-availability at the time of data collection and 6) absconding fathers.

Much as these categories of respondents could not be interviewed, the diverse backgrounds to the sample of this study and the experiences within their varied socio-cultural context provides a rich array of data that could be of help in understanding the experiences of fathers of SCD within the African milieu. Though in this study, a majority (25) of the respondents were of low socio-economic backgrounds and just a few belonged to the middle-income group (5) and only one to the high-income group (F9), individual accounts suggest that people's experiences with SCD was highly dependent on the course of the disease in the child and the social context within which they found themselves, rather than being dictated by the socio-economic background alone.

The situation of absconding fathers being reportedly common was further investigated towards the completion of the main study. The data gathered indicated that absconding due to SCD was relatively rare among fathers, and that reasons for absconding most often lay with discord and discontent between partners rather than the birth of the SCD child. However, challenges associated with SCD care tended to

incite or aggravate existing discord between the couple. This implies that the limited number of absconding fathers interviewed in the final sample does not necessarily detract from the possibility of generalising lessons from this study to the wider population of affected families with SCD in Ghana.

Conclusion

The first two chapters have provided the reader with a vivid description of the relevance of the study entitled “*The social meanings of a child with sickle cell disease in Ghana: fathers’ reactions and perspectives*”; what literature exists to clarify the issue of social aspects of SCD as well as an outline of the strategy and methods the researcher used in generating data on the study topic.

This chapter has narrated the strategy used in the study of thirty-one fathers, nine mothers and seven health workers in determining the subject under investigation. This has offered the reader the opportunity to come to know the rich and diverse experiences and challenges the researcher faced in conducting the study. In the ensuing chapters, the researcher examines and discusses the data that was generated through the study with respect to themes such as the context of traditional courtship, marriage, division of labour and childbearing. Other themes that will be covered include health, illness and SCD as a chronic condition, learning to understand SCD after childbirth, beyond the horizon of care, social beliefs on SCD and their implications for paternal care, the social meanings of fathering a child with SCD, among others. It is through these data that the relevant conclusions and recommendations will be drawn with reference to existing literature.

CHAPTER FOUR:

THE CONTEXT OF TRADITIONAL COURTSHIP, MARRIAGE, CHILDREN AND FAMILY DIVISION OF LABOUR

In the previous chapter, the researcher discussed the epistemological basis for the choice of strategy and methods selected for the study. She also outlined the choice of data collection and analysis methods and clarified the possible influences her own identity might have introduced into the conduct of the study. The next three chapters, four, five and six, describe the series of findings generated from the interviews with the thirty-one fathers, a group of nine mothers and seven specialist HCWs.

The analysis generated fourteen themes in total, which have been further aggregated into three main theoretical constructs. The fourteen themes were so distributed in view of their emerging meanings, congruence and relationship to each other. Besides, their contents flow into each other within a construct and enrich the meanings given to a construct in a symbiotic manner. The broader constructs include: 1) The Context of Traditional Courtship, Marriage, Children and Family Division of Labour 2) The Social Meanings of Health, Illness and SCD and 3) The Social Impact of SCD on Fathers.

The first construct comprised four themes, namely i) Traditional Courtship and Marriage ii) Religion and Marriage iii) Symbolic Value of Children in Marriage and iv) Role of Fathers in Childcare and Division of Labour. The second theoretical construct was generated from four themes that emerged, including: i) Social Concept of Health and Illness ii) Knowledge of SCD and its Meanings to Marriage and

Childbirth iii) Learning to Understand SCD after Childbirth iv) Social Beliefs on SCD and their Implications for Paternal Care. The third theoretical construct focusing on the Social Impact of SCD was a composite of six emerging themes, namely i) The Social Meaning of Fathering a Child with SCD ii) Extending Care to an SCD child iii) Challenges associated with Paternal Care iv) Beyond the Horizon of SCD and Family Relationships v) Coping Systems in Fathering a Child with SCD and vi) Fathers' Recommendations for Health and Social Services

This chapter describes findings of the study pertaining to the first of these three broad constructs, namely traditional courtship, marriage, children and family division of labour. It presents respondents' experiences and perceptions regarding traditional rites for marriage, the meanings they attach to marriage and pregnancy; the symbolic value of child bearing; social influences on division of labour in contemporary Ghana; and extent of religious influence on marriages. In each of the three analysis chapters, themes have been discussed and further illustrated with respondents' quotations. Generally, whilst the findings remain commensurate with the available literature on families, traditional marriage and division of labour, they also provide an in-depth knowledge on fathers' beliefs, perceptions, greatest challenges and reactions to SCD, fears and ultimately their hopes for their children; all of which had previously remained largely undocumented.

'Mpena twe' and 'Aware': Traditional Courtship and Marriage

Marriage in Ghana is an institution that brings both families of the would-be-couple together and to that extent is not regarded as a private relationship between the two (Kuada and Chacha, 1989). It is considered too important to be left entirely to the

couple because it is the beginning of a new lineage or community and the blessings of the elders and ancestors must be sought. In contemporary Ghana, where arranged marriages are becoming outdated, most marriages begin with courtship. This may be a known or often unknown relationship to parents in the initial stages of development. In the cases of the thirty-one fathers of children with SCD, the researcher sought to identify the series of steps that led to marriage between the Ghanaian young man and woman. Interest in these steps was generated through the findings of the pilot study that drew the researcher's attention to this as a key process influencing later experiences of having a child with SCD.

Courtship

In the study, findings indicated that a majority (20) of the fathers courted their women for varying periods of time before the actual traditional marriage took place. In the course of the interviews, the phenomenon of courtship was explained locally as '*mpeña twe*' meaning stealing access to the girl without the consent of parents.

"The traditional courtship (mpeña twe) is a relationship between the man and woman for which the girl's parents are not officially aware of. Literally the man is considered as stealing access to the girl. But the right approach is to perform the marriage rites. (F22)

"It means someone you have not formally married but you have regular and steady including sexual relationship with". (F21)

All the mothers (9) interviewed through focus group discussion implied a period of courtship in their relationship with the fathers of their SCD children. Of the remaining eleven fathers none explicitly stated that their relationships started with courtship. Rather, they dwelt on the issue of their women consenting to being their lovers based on which they sought permission from their families to perform the marriage rites.

All respondents gave evidence to that effect during courtship or at the point of marriage. The elements of proposing and consenting were presented as gender-defined activities probably set by culture and tradition. The men had the responsibility to propose whilst the women consented. None of the mothers indicated that they were interested in the husbands when they first met and therefore did not approach their future husbands to express amorous thoughts. The men took the first step.

Also implicit in Ghanaian courtship was the element of sexual relationship between the lovers though marriage had not taken place. This was evident among the respondents interviewed as about a third (9) of the fathers reported getting their women pregnant in the course of courtship. Some had had two children with the women and had still not married them. F4 and F5 described their situations as follows:

“I met her in 1983 in Kumasi though we hail from the same town. I was then a bus conductor. We started a relationship and in the course of it she got pregnant. Around that time, I had just started going to church and was therefore scared that if the church got to know of that pregnancy, I would be suspended so I quickly mobilised some money and went to perform the traditional marriage rites”. [F4]

“Whilst we were in this relationship, she got pregnant and I went to perform the marriage rites. Usually when a girl is put in the family way, her family will ask her who is responsible and they would come to that person’s family to enquire. If the gentleman accepts his responsibility then his family is requested to perform the marriage rites, and this differs from ethnic group to ethnic group. I performed the marriage according to the Ga tradition because she is a Ga but I have forgotten what the ceremony entailed because it was done a long time ago (1972)”. [F21]

Apart from the occurrence of pregnancy during courtship, fathers interviewed ascribed other reasons such as ‘*Obaa ne ho dwo*’ (woman with humble attitudes), ‘*N’ani da fam*’ (modesty), ‘*Odi ne ho ni na ne ho ye fe*’ (decency and beauty) as being other reasons for marriage.

Marriage was also perceived as a means for having companionship, support and a stable environment within which to bear and nurture children. To enter marriage, one must be prepared by planning ahead of time so that the right procedures would be followed (avoiding fornication and pregnancy before marriage). Most of the men met their partners through familiarity resulting from living at same vicinity, their regular jobs, testimonies from friends or domestic services being offered by the women e.g. cooking. To support that F 19 said:

“I went to Kwahu Tafo for my national service. My wife is the daughter of a Presbyterian Minister. I saw her then but my mind was not on marriage then. However when I was posted to Kumasi and I began contemplating marriage she came to mind because of her humility (Obaa ne ho dwo) and modesty (N’ani da fam)”

The fathers sought to perform the marriage rites according to the requirements of the ethnic group their women belonged to in order to marry the women they have been courting. There is an initial rite referred to as ‘knocking’ which they perform to formally gain recognition from the woman’s family. The knocking rites (*Kokooko* in Twi) confer family recognition from the woman’s side on the man but not the status of husband. F10 explained ‘*kokooko*’ as follows:

“There is a difference between customary marriage (‘aware’ in Twi) rites and knocking rites. Knocking rites entail your going to introduce yourself to the woman’s family with some few drinks to formally inform them that you are courting their daughter so if they are looking for her she is with you. In this instance, you don’t go with so many people. It may be just you the man and your father or another senior relative. You also promise that all things being equal you will come and perform the customary rites at an agreed time. The drink that the man brings is traditionally not opened. It serves as witness to the request so that in case the man proves irresponsible later, they can return that same drink and nullify the relationship”.

After an unspecified time period ranging from few days, weeks to a few years, the man is expected to come forward to perform the actual marriage rites. Some men however, do not progress beyond the knocking stage and yet enjoy the full benefit of marriage, though the woman’s family may frown upon the attitude.

Findings indicated that a few fathers (3) had had babies in such circumstances and still lived with the women as their ‘wives’.

Traditional Marriage

According to the fathers studied, the traditional Ghanaian marriage is a transaction between the families of the man and the woman. On an appointed date the two families and selected friends meet in the house of the bride’s relative (father or maternal uncle) for the performance of the rites. As part of the ceremony the bride will give a verbal consent and confirm her desire to marry the groom in the presence of all gathered at the ceremony. The two families present act as witnesses to the marriage as the dowry is paid to the bride’s family. It is worth noting that the value of dowries varies from one ethnic community to the other and not fixed in terms of cost. Even within a particular community, the type of dowry presented at a marriage ceremony is increasingly dependant on the social status of the man and woman. It could be as high as ninety percent (90%) of the annual per capita income (25,000,000 cedis) in Ghana. that is about one thousand five hundred pounds (£1,500), or as low as one percent (1%), that is an equivalent of about twenty-five pounds (£25). The marriage is consummated only if the dowry is accepted and verbal appreciation expressed to the groom’s family. A description by F10 provides a vivid picture of a Ghanaian traditional marriage.

“I approached her parents with my family and they agreed to my proposal to marry their daughter. At the appointed time my family and hers met and I performed the marriage rites.

As rites, the woman’s family requested for some drinks, money and other items including a token for her father, token for mother, brothers-in-law, the wider family and then the bride price. I converted all these requests into monetary value as I did not believe in submitting alcoholic drinks.

You see the most important thing in this ceremony is for the woman to accept to marry you. Without that verbal expression of acceptance, the family cannot accept the items and money brought by the man and his family. When the items have been

accepted, the woman's family then express their appreciation as a final step. This ceremony is what entitles you to call her your wife".

The narratives of the fathers on traditional courtship and marriage suggest a laid down traditional procedure towards marriage. This procedure is distinctively set in four stages: courtship, knocking, traditional marriage and civil marriage (optional). Though the procedure was well known to the fathers, it was evident that not all of them adhered to it. Besides, babies therefore were being born before or after any of these stages with out any reflection on their genetic constitution: a concept generally foreign to them, though it is assumed by genetics authors in Western Countries that it is a "good thing" for carrier status to be widely known by people in the community before having a child/marriage. These attitudes of the fathers raise implications for health and social policies intended to encourage people from the stage of young adulthood onwards to know their carrier status for SCD. Such policies would need to take account of the potential (and perhaps unintended) consequences of genetic information in interaction with each of these stages. It would also need to take into consideration appropriate timing for introducing communities to the concept of genetics and its relevance to childbearing and SCD.

In the following section, the researcher proceeds to draw attention to the perceived relevance of religion in marriage and how that influences the preparation of the fathers interviewed towards marriage.

‘Not indulging in illicit relationship’: Religion and Marriage

Implicit in the conduct of the traditional marriage are the values and religious beliefs that the performers bring to bear on the celebration. The religious beliefs of the couple and the parents of the bride determine what form the dowry to be paid would take. Traditionally, the groom would be expected to present some alcoholic beverages as part of the dowry. But where family religious beliefs singly or collectively conflict with alcohol intake, a prior decision would be made to present the dowry in monetary value or for the groom to provide only non-alcoholic beverages.

Values and beliefs

Values and beliefs also influence the type of courtship that will be exhibited by the couple. Two of the fathers reported that because of their religious beliefs, their courtship was devoid of sexual relationships. They perceived it as fornication which was against the doctrines of their church.

“.....Customarily, when a man sees a woman he is interested in, he informs his immediate family and does not indulge in any illicit activity like fornication”. [F19]

For those who had been involved in sex during courtship, they had a tendency to hurriedly perform the traditional marriage rites to avoid disciplinary measures taken against them by their church. These measures range from publicly informing the church of what is perceived as the immoral act to suspension from any leadership position one may hold. Another reason for the hurry was to avoid the passing of social judgement on the man and woman as being irresponsible, indecent and undisciplined. The following statement attests to this finding.

“We started a relationship and in the course of it she got pregnant. Around that time, I had just started going to church and was therefore scared that if the church got to know of that pregnancy, I would be suspended so I quickly mobilised some money and went to perform the traditional marriage rites”. [F4]

The next level of marriage that was mentioned by the respondents was the marriage of ordinance (commonly the church wedding).

Marriage of Ordinance

This marriage, though optional, was viewed as very important by the Pentecostal denominations of the Christian fraternity. It was contracted after the traditional marriage and could only be performed as such because it was culturally unacceptable for a church wedding to be conducted when both families have not traditionally consummated the marriage. Prior to the wedding, the couple go through marriage counselling organised by the church to prepare the couple spiritually and morally towards marriage. According to respondents (fathers and mothers), embedded in the counselling activity is the optional request for the couple to test to know their blood type, sickle cell status and possibly their HIV status.

Though counselling prior to marriage was reported to be common in all the Christian churches, fathers noted that request for testing was predominant in the Pentecostal denominations of the Christian fraternity. However, most (19) fathers did not have the opportunity to benefit from this test because at the time of their marriage, churches were not giving such recommendations to their counselees. Besides, this practice seemed to be a recent introduction to churches and not so widespread in the orthodox (Presbyterian, Methodist and Catholic) denominations. F30 expresses this as follows:

“My church did nothing really about us getting tested. Our church did not have that policy” [F30]

These findings on religion and marriage suggest the important role that personal beliefs play in determining preparation towards marriage and the extent to which the type of religious denomination one belongs to influences the uptake of screening

services such as testing for SCD status. This implies that programmes looking at increasing uptake of screening for sickle cell status could partner with religious organisations in accessing eligible populations.

Whether the desire to court and marry as a genuine expression of love and admiration of the woman or to cover up for a pregnancy to avoid unacceptable social repercussions, the underlying factor remains the issue of bearing children: a perceived inseparable gift to every marriage. The symbolic value of children and the attendant implications for SCD are discussed in the section that follows.

‘A man without a child is often not very much honoured’: The Symbolic Value of Children in Marriage

Marriage and childbirth are the two most important cultural expectations of every Ghanaian young adult. There must come a time in the life of the Ghanaian when he or she is expected to marry and bear children to continue the lineage (Kuada and Chacha, 1989). This statement was true for the fathers interviewed and supported by the mothers. In their narration of their feelings concerning children in marriage, all thirty-one fathers implied that children were a blessing from God to a married couple, a consummation of mutual love, honourable when present in a marriage and had the capacity to immortalise the names of their parents in future through their achievements. Children again ensured a continuation to the lineage and provided ‘insurance’ for subsistence and support to the parents in their old age. Children were considered so important and key for the survival of marriages in Africa.

Child-bearing and marriage were also perceived as a progression in one's life that must be fulfilled, and a source of discipline to protect and sustain one's health as marriage compels the couple to settle down with each other. Marriage was also perceived as a means to gaining more experience and maturity in life.

Childbirth

According to the fathers, feelings on childbirth were so strong that the announcement of pregnancy by the wife or partner was greeted with excitement and appreciation especially when the man felt financially stable to provide for the child's health, nutrition, education and other basic needs. The climax of their excitement was when the baby was born safely, normally (without any caesarean operation which would incur additional debt), the sex is what has been wished for and the man can meet the expected financial obligations. They used expressions such as '*It's natural that when you reach a certain age you have to settle down and marry and have children*'; '*As a human being in this world, it is important that you have a child or two*'; '*A man without a child is often not very much honoured*', and '*When a couple marries, the next thing for them is to have a child because they are the future benefit*' to express their feelings about children in marriage.

Though preference for a particular gender was not strongly reflected in the reports of the fathers, one commented that the male gender is important in patrilineal ethnic communities where men are expected to keep family compounds and inherit property. However in most of contemporary Ghana, preference for a particular gender at birth is gradually being eroded and couples are often happy with families comprising both girls and boys.

In his account of childrearing, F9 made special reference to marriage as a ‘discipline’ that *‘holds you in check in the present times of diseases all over’*. This statement he made as a means towards drawing attention to the global scourge of sexually transmitted diseases (STDs) especially HIV/AIDS and how he believed marriage could be protective cover in preventing infection. He argued that:

“It’s natural that when you reach a certain age you have to settle down and marry and have children. As human beings, marriage is a progression in our lives that keeps us in check. You settle down to one woman. Marriage is a discipline. When you are not married you will think you can be disciplined but you can’t unless you have been called to some form of priesthood. In these present times with diseases all over, it is a difficult thing if you are not married” [F9]

The belief of F9 appears strongly and sincerely held, though it is not necessarily true as marriage could only be a protective cover in preventing STDs when couples are committed to honesty and faithfulness.

Another significant value of children in marriage is that they represent a confirmation of the virility of the man, especially if the child is the first one. Childbirth brings along with it a sign of social respect and recognition that the man has an experience of fatherhood and can therefore make worthwhile contributions to matters of childbearing. A sixty-five year old father of five children (two with SCD) who was interviewed expressed his keen excitement when his wife announced that she was pregnant with their first child.

“Anybody who has never had a child feels excited with his first child. You have added on to the family. So I was very happy. It shows that you are a man (virile). Having the child meant a father’s benefit. Without a child you are not respected. Children give you honour” [F21]

The notion of deciding not have any child at all was noted to have unacceptable traditional implications. Often the woman incurs the wrath of her parents-in-law for

reasons outline above. Childlessness is perceived as unacceptable and a waste of one's reproductive system (Sarpong, 1974).

In contemporary Ghana, society is gradually changing and being receptive to childless couples. The following statement reflects some current level of acceptability depending on one's belief.

“Childbearing is part of God's laid down plan for marriage. The bible describes God's command for us to bear children to replenish the earth. At the same time, we are admonished that not all women will necessarily bear children. Children are a blessing to marriage but not the purpose for marriage so if for some reason someone does not get some, the person must not be held to it”. [F19]

Deciding on the number of children to have

Much as fathers' statements reflected a positive and strong desire by couples to have children, they also pondered in their minds on the number of children to have.

F5 said:

“I had an intention to have children. As a human being in this world, it is important that you have a child or two. So I was interested in children but I knew that having too many children would not help me. When my wife had her baby, I was then in Nigeria. I was very happy to hear of it. My friends and I organised a party back then and celebrated the birth. The baby was a boy and that was what I wanted. I understood it to be happy news. It's expected. It's normal” I feel it is a gift from God. In our Ghanaian culture, when you marry you must have children. So if God has blessed us with one. We should consider it as a blessing of our marriage”.

The decision on the number of children to have was often made by the couple but may be revised in the course of the marriage depending on new contextual factors that impinge on the situation, of which the birth of a child with SCD is a major one. In the descriptions given by the fathers, SCD was presented as a condition that had led to a disruption of their 'moral career' to have the number of children they would have desired. Other factors included requests from significant members of family and the

provision of material or financial support. One father and another mother made similar statements that suggest the role that SCD plays in decisions on child bearing.

They reported as follows:

“I told my husband after marriage that we should have about 4 children so we can adequately cater for them. But because of this child with SCD, this thinking has changed. We have decided to settle on 3 children so we can cater for them” (M 3).

“My in-laws do not have a large family so they are even happy that we have 5 children. My wife’s aunt had no child so even when I decided not to have more because of SCD she virtually begged me to give their family more children. She even said that when my eldest daughter graduates from high school she would adopt her. They are happy with my children and even she sends them dresses at Christmas. Just recently, she called me and said “I have been able to make some building blocks. They are for your wife and children. Whenever by God’s grace you get some money, please come and take them for a building. She is the pillar of their family” (F4).

On the other hand some couples remained firm in their decision even in the face of SCD. Two fathers had this to say:

“My main view of marriage was to get a partner with whom I could bear children. Childbearing was of prime importance with the expectation that I would care for these children to responsible adulthood so that they would in turn care for me when I am old. These feelings have not changed despite the fact that I now have an SCD child” [F14]

“[...] So as to whether the child will be normal or abnormal, we have a responsibility to care for that child. I was aware that in marriage you would not have all children being perfect” [F29]

This suggests that the experience of having a child with SCD is only one of a number of contextual factors in family planning, and may or may not be a decisive one, according to different family circumstance.

Social Context of Childbirth

There are, however, a few occasions when the announcement of pregnancy is not greeted with excitement and enthusiasm. This is much influenced by the circumstances surrounding the relationship and the motive of the man for going into

the relationship as to his level of preparedness for settling into a married life. During the interviews the researcher encountered three fathers who were dissatisfied with the circumstances surrounding the birth of their children. Statements made by this group of fathers to this effect included the following:

“Erm! Erm!! You know at the initial stage of the pregnancy, the woman did not even inform me that she was pregnant. Her siblings informed me and I asked her several times but she denied it. So I took her to the hospital for confirmation. I must say that her pregnancy at first was unwelcome news to me because my intention was not to have a child then but to be in a relationship with her. Then she got pregnant and hid the information from me. Everything just took me by surprise. By the time I got to confirming it, the pregnancy was about 6 months old” [F16]

When we arrived in Ghana from Nigeria, it was the military that were in power. Studying the political situation, I realised that it would be unsafe for me to deny the pregnancy within the circumstances surrounding how we met and lived in Nigeria. So to avoid any complications, I accepted the pregnancy.She was not necessarily the woman I would have desired to marry. Her marrying was circumstantial viz the political climate. But concerning childbirth, I love children. My children are very dear to me. [F23]

“To be frank as at that time, I was young and unready for children but what will you do when it happens? And it was not that I did not like the child, it was rather the timing that made it a problem” [F28]

From their accounts, one could discern that F16 certainly seemed bitter; F23 seemed more resigned than bitter, whilst F28 seemed unprepared for children at the time of pregnancy. These fathers present three different social contexts within which the birth of a child with SCD could be highly unwanted resulting in problems with childcare and support. Though none of them indicated that they disliked children, the circumstances surrounding the pregnancy diminished the interest and enthusiasm with which they received the news of pregnancy. Implicit in these statements is the need for SCD programmes to promote childbearing under the umbrella of marriage rather than courtship. This is because under the auspices of marriage, the couple are committed to each other and prepared for children.

So far in this chapter, the researcher has argued that, symbolically, children are enviable treasures, very precious to the survival of Ghanaian marriages and perceived as a gift from God. Also, without children, women feel insecure and emotionally disturbed in their marriages and men feel incomplete and unfulfilled. Findings have also shown that extended family relationships may be strained because of childlessness. It was also evident that children are a source of joy to couples and their hope for future insurance towards basic needs. It was also found that pregnancy was welcome within the right circumstances and unwelcome when one of the couple feels cheated, unprepared or uninformed. Financial resources, birth of a SCD child or persistent pressure from family may all result in a disruption in their moral career, that is, in the expectations fathers have of how their lives will develop. However, fathers also believed and understood that childbirth conferred on them certain social and spiritual responsibilities which they must fulfil in order to secure the future benefits to be accrued to them if their children become successful.

The next section examines the specific role of fathers in childcare and division of labour as part of these social and spiritual responsibilities and the factors that influence them.

‘A call to social and spiritual duty’: The Role of Fathers in Childcare and the Division of Labour

The traditional expectation of the man, according to the literature, is to provide for spiritual leadership, security, food, clothing, shelter and health of his wife and

children. The couple are also expected to socialise the child, enforce norms and laws, instil religious practices and transmit cultural heritage (Boateng, 1996; Brown, 1996). In this last section of the chapter, findings are presented with respect to fathers' understanding of what their roles in childcare and keeping household are, how they try to play these roles, and the challenges they face carrying out these traditionally-assigned roles are discussed. Mothers' perceptions on these roles and what they perceive as their husbands' actual contributions to house keeping and childcare have also been outlined and their implications for SCD drawn.

Childbirth: A call to duty

According to the fathers studied, childbirth meant a call to social and spiritual duty. They believed that as spiritual heads of their families, they were accountable to God their creator for the upkeep of their children. In their reports, all the fathers interviewed described their primary role in childcare to include provision of food, clothing, shelter and comfort for the family. Other responsibilities listed by fathers were provision for education, health care and guidance towards responsible adulthood. Some said:

“Having a child means a continuation of your family tree line. Having a baby has spiritual connotation. It confers on you your spiritual position in the family as the head” [F9]

“Having a child meant a precious treasure that I had to cherish and to nurture into a valuable person; to protect and guide him to become what he wants to be. [F10]

Although the fathers vividly described their roles as traditionally and spiritually conferred, two fathers aged thirty-six and forty-one respectively and each with one SCD child added that although these roles came with challenges, they were nonetheless prepared to face their responsibilities all the way with faithfulness and commitment.

“The child meant a lot to me because I knew whatever be the case I have a responsibility to care for it into adulthood so I was prepared to face any challenges that came my way in his upbringing”. [F18]

The child is my own blood, someone who will help me when he grows up into an adult. For him to be able to do that, it all depends on me as a father. I have to be committed and faithful to this child to provide all his needs. Even if I can't afford it, I can show love to him and he will grow up to appreciate it. When a child is born, he must be clothed, fed and kept healthy. There are so many things to do”. [F20]

Only one father amongst the thirty-one interviewed expressed negative sentiments about what it meant to have a child with SCD., The thirty-seven year old father of three recounted that the birth of his six year old first child (with SCD) was a source of punishment to him and therefore he was not enthusiastic about playing his role as a father though he is trying his best. A reflection on the total circumstance surrounding the birth of his SCD child with a woman he courted but did not marry was the basis of these feelings. He felt embittered, and had this to say:

“When we were going to the hospital, I had the impression that she was having a problem with the pregnancy: say bleeding only to get there and be told she the baby was coming. In fact, having that child in the beginning felt like punishment to me. I felt the lady had punished me if I reflected on the whole circumstance of the pregnancy and childbirth”. [F16]

It could be inferred from previous statements of F16 that he is a father who felt he had been tricked by virtue of the mother of his child hiding her pregnancy from him. The interpretation the researcher places on this father's reaction to SCD as a condition is that this experience exacerbated an already existing grievance rather than initiated that grievance. That means that the presence of SCD in the child worsened an already strained relationship.

Traditional Division of Labour

The findings of the research clearly marked out a traditionally defined distinction of maternal and paternal roles in the domestic division of labour. All the fathers (23)

who lived under the same roof with their children noted that typically in their day, they would *check* that their children were fine, *confirm* that they had eaten, taken medications if applicable and *ensured* that they were going about their routines for the day such as going to the farm, washing, playing, helping with household chores or going to school. In the evenings upon return from work, the fathers reported that they would find out how the children got on at school, help them to do any homework from school if applicable, do some reading or watch TV with the family after dinner. Where possible, they would all chat or play indoor games.

Generally, the fathers felt that they had a duty to plant and maintain discipline in the house. They would therefore keep a disciplinary eye, observe all the children and ensure they were doing the right thing. Moral uprightness was also perceived as a duty. They shared life experiences with the children and advised them on the repercussions of adverse behaviour. For those who were staunch Christians, they shared bible teachings with the children and prayed with them for God's protection, security and guidance. A forty-two year old father of three children said:

"I check on the children and if there is anybody who has to take medication, I give it and see them off to school" (F 2)

Another forty-four year old father of four children had this to say:

"In the morning, I check that everybody in the household is in good health. Then I make sure that all that is needed for the children's upkeep and school are available for the day. This is what I believe a father must do and that is what I do. In the evenings I enquire from the family how the day has been and I take appropriate action". [F6]

On moral discipline, two fathers explained their roles as follows:

"Concerning the children, I try to discipline them when necessary. I teach them biblical principles. I am a Sunday school teacher so I am particular about their discipline, school work and their behaviour. Where they fall short, I teach them the right way". [F7]

I usually advise the older ones on moral and upright behaviour and to be serious with their books" (F 2)

Of the remaining seven who did not live with some or all their children, they had relinquished these responsibilities to the mothers of the children or their guardians. Such fathers claimed they were able to undertake their duties from a distance and felt helpless sometimes when things did not work out to their expectations.

“But for those I live with, their daily needs are on my mind every time and I see to that. I actually do not live with this wife so I can’t say much about the evenings. For her, I give monthly allowance towards the upkeep of the child and in-between the month if there are any needs I try my possible best to provide. I don’t work on Sundays so those are days I am able to meet with the child and find out how she is doing. Sometimes we take a stroll together or when I go to town and I meet her and the mum and she comes to me”. [F20]

For some of the fathers, their ability to carry out their duty as traditionally defined became undermined when there was a separation between them and their wives. This worsened with the persistence of unresolved issues. A forty-nine year old father of six children, a driver and a divorcee of the mother with whom he had had 4 of his children including the one with SCD had this story to tell.

“Every morning I would check that the children are well and ready for school. I give them their daily lunch allowance and they go off to school. When I am away on the road, then their mother takes care of all that. I was doing this for all of them until this separation between their mother and I occurred.

When it happened, I requested to adopt the 2 younger children including the one with SCD to come and live with me. The first 2 were a bit mature so I felt they could manage as young adults. The first child was then 22years. But their mother refused for me to take the children away and indicated that if because of this refusal I decide not to care for the children she will do that herself. In the course of all the confusion, the SCD child got sick and the mother could not come to me for financial support. I also pretended I had not heard that the child was sick. But later, I decided it was not worth fighting for the children, after all they are mine. So they are all with their mother and I take care of their every need. I send money to her regularly for their upkeep”. [F23]

In the fathers’ accounts on their role in household division of labour, it is apparent that they tried to carry out their responsibilities even in the face of separation by distance from their children. However they acknowledged that playing their role by proxy, that is through the mother of the child or relative with whom the child is living, had its own associated challenges which worsened in the presence of strained relationships. It also seemed that SCD care became incorporated into the everyday life

of the men without much agitation. These findings suggest a diversity of ways through which SCD programmes could positively harness paternal desires to be involved in managing SCD at home.

In an attempt to find out from the fathers what their wives did in the house as part of traditional division of labour, the researcher asked them to indicate their wife's role in childcare as well. In their accounts, they recounted that whilst they check, confirm, ensure and advise, their wives were engaged in physically carrying out the household chores such as cooking, tidying, dressing the children and washing. Their wives also support them financially in meeting the basic care of the children.

Interestingly, and contrary to the fathers' reports, most of the mothers interviewed noted that their husbands commonly did nothing in the house apart from meeting their financial and supervisory obligations. They, the women, performed the household chores whilst their husbands chatted with friends, read newspapers or watched television. These contrary presentations from the men and women could be explained, from the researcher's perspective, by the tendency for women to perceive the accounts given by the fathers as representing intangible tasks that did not involve 'hands-on' tasks, whilst the men perceive the supervisory roles described as very laudable tasks. Therefore it is possible to argue that gender perceptions to household tasks and division of labour are highly specific. Whilst women perceive tangible tasks as contributing to household work, the men were convinced their intangible activities were equally important to the household. The accounts given by the men could also be related to their perception of the researcher's identity. One could say that the men tried to present themselves as morally worthy persons since they were being

interviewed by someone they perceived as both a woman and as a professional with high standing.

Fathers' involvement in household activities

Two women had a different view of their husbands. They said:

“For me, my husband is very supportive in the house. When the child is crying, he either picks her up or gives her to me and goes to attend to what I was doing before” (M 6)

A further outcome of some fathers' ability to support their wives in the dispensation of their traditionally assigned roles as wives was the flexibility with which the couples negotiated for their roles under the umbrella of marriage. Couples were also able to create an atmosphere of symbiosis whereby the women would help financially or perform certain tasks which used to be traditionally perceived as the men's role. A typical example is paying school fees or paying hospital bills.

One of the mothers interviewed reported that she and her husband were able to come to an agreement as to who does what in the house. This opportunity for negotiation is not traditionally tolerated, as the woman is perceived in the African tradition to be subservient to the man. Therefore it could be considered rude of her to have even attempted to enter into negotiation on matters such as roles. Often, men would not attempt at all to help their wives in the house to avoid the situation where their wives begun to take them for granted and make requests for tasks to be performed. Hence, the common attitude of reading, hanging out with their friends, watching TV or reading the tabloids.

“My husband usually irons the clothing I wash. He would always ensure the children's school uniforms are neatly ironed and their shoes polished. It is the man's responsibility to do these things. We arrived at these shared responsibilities through mutual

agreement. Often he irons and polishes his shoes so I asked him to do that for the children as well and he agreed. So that has been the order. We both decided we would take care of our child. That time, I was a hairdresser so whatever the child needed I was able to provide. Even when the child needed to be taken to the hospital and my husband has not brought any money I will take my own money and go.

When my husband returns to the house he would reimburse me. He has played his role as a father responsibly. Presently this child is in school and doing well". [M5]

A few (5) of the fathers confirmed this positive testimony given by the mothers by reporting the exceptional support they have been giving to their wives. This support was perceived to be motivated by a personal belief to help their wives rather than a request by wives to be supported as such requests are seen as acts of compulsion and interpreted to mean being ‘bossed around’.

One father said:

“When the child cries in the night, I would get up and pet him. Washing and changing nappies was not a problem to me so was feeding the baby. For all my 3 children I did it for them. Traditionally, each of us has roles to play. The man has a responsibility to provide the needs of the child especially financially. In the olden days, the little money that the man contributed to the upkeep of the house was enough and the woman did not have to work. But now this is not possible. The woman has to work too.I have a different view and that is to help in whatever way I can in house hold chores to make life easy for all of us. So I help. But that is not to say that I allow the woman to be bossing me around to do this or that (F7).

Others made the following comments:

“When I feel that it is a long time since they ate a particular food, I would come to Kumasi and buy some for them. My children are very fond of me compared to their mother because of the way I care for and treat them. Their mother is often busy in the market. I am the one they often meet and relate with so they like me a lot”. [F4- forty-eight year old father of 5 children. Two of them have SCD]

“I support my wife in the house. In the mornings whilst she is busy bathing the child or getting food ready, I do the washing of clothing if necessary. Then we all go to work. In the evening, it’s the same. If it is cooking, I may hold the child whilst she is busy or help with the cooking like pounding fufu. So even the people in our house comment on how beautiful our marriage is. On Saturdays, I go to work. It is only Sundays which are my free days. We visit our families, catch up on social activities (funerals, weddings, visitations) and or sort out any household tasks that are outstanding” [F11- thirty-seven year old father of one child with SCD]

Another dimension to the supportive role of fathers was evident in their stories.

Fathers’ interest to support their wives, though genuine and desired, may be inhibited

to a large extent by social norms and values that ascribe limitations to what is acceptable as a man's support in the house. To avoid these criticisms, men who want to help would do it under cover of prying eyes.

There are reports from the researcher's social context in Ghana of extreme castigations and violence by the man's relations towards women who allow their men to perform women's tasks, labelling such women as 'w'aye ne kuno no aduro' meaning they have cast a magic spell on their husbands or have charmed them. It is believed that in marriages where the men are very obliging and would do every bidding of the woman, such men have been put under a spell by their women. In such situations, the men's families do not look favourably on the women. Hence the castigations.

"By God's Grace, we have some cousins, nephews and nieces who live with us and support us. But even before they came I was very supportive of my wife. There have been times I have tidied the living and bedroom and even cooked for the family. I don't sweep outside because people may see and comment that how can a man of God be sweeping like that. But I help my wife. If she is occupied doing something, I do other things in the house. In the evenings on days when I do not travel outside home (you know the work of a minister is full of travel) I help her in the household chores as I have already stated. Cooking when it was only the 2 of us with no children. When we had our first child, I'd hold the child when she is busy doing something. Even in the dead of nights when the child is fretful I'd hold her and cuddle her to sleep whilst my wife rests. I have even carried my baby at my back before. Now, I help more with school homework and joining the family to carry out cleaning or something together. Now because of the relatives in the house I am not that involved as much as I used to". [F19- a forty-four year old father of 2. First child with SCD]

This information does offer implications for promoting paternal involvement in SCD childcare in that SCD programmes will need to increasingly devise strategies for integrating the fathers in a socially inoffensive way.

There was yet another category of fathers who seemed not to participate in childcare. Their contributions were virtually non-existent or just financial. Such fathers would wake up in the morning, wash down, iron their outfit and go off to work. They would fill their leisure with visiting friends and family because their children were too young for them to actively care for them. They felt that the best place for the baby to be was with its mother. Implicit in their accounts were the strong conviction that traditionally fathers were there to meet the financial needs of their families. The greater part of household responsibilities lay with the mother.

“In the morning, I iron my day’s outfit, take my bath and go to work. When I return from work in the evening, I eat, wash down and sleep. Over the weekends I go to work on Saturdays for half day. On Sundays, I go to church in the mornings and in the afternoons I socialize with friends and family. My present baby is about 6 months”. [F16-thirty-seven year old father of 3, one with SCD]

“Even till today, I wake up around 4am, go to the washroom, take my bath, have a cup of tea, go to church for morning mass and proceed to the workplace. When my kids were younger, I would check that the mother has rallied everybody ready for school, I get them some lunch allowance then I leave for work” [F22-seventy year old father of 16 children, three with SCD, two dead]

Nurturing and Disciplining Children: A father’s role

In the interviews, the researcher also sought to identify fathers’ perception of child-rearing and nurturing, and findings indicated that the fathers perceived nurturing and bringing up the child into responsible adulthood as an important duty. However, the assumption of that responsibility was dependent on the age of the child. The fathers felt that the younger the child, the better it was for the mother to begin the nurturing process. As the children reached school age, they would then continue because at that age, it was easy to communicate and train. Four main aspects to nurturing were described by the fathers. These were paying attention to their education, instilling in them the appropriate respect for God, advising and counselling and finally disciplining recalcitrant behaviour. One father noted that there is no particular art for

nurturing children but rather a dynamic process that involves adapting the nurturing style to what has worked with other fathers and the changing trends in culture and socialisation.

“As for child upbringing, you learn it from others. As you see the way other people raise their children and you feel it is good you adopt that strategy. Right now their schooling is very important to me” [F27]

In paying attention to their children’s education, fathers helped their children to complete their homework and kept in touch with their schools to keep track of their progress. Education of children was perceived as an obligation irrespective of whether a father could afford or not. It was felt that a father should always aim at educating the child to a level higher than the parents themselves had reached.

“...Another important area is their education. Whether you can afford it or not, when you have children, you must aim at educating them to a level higher than where you got to” [F28]

“As he is a youngster, the prime challenge is his schooling. So I do all that I think a parent should do for his child. I am very particular about his feeding, schooling, clothing and money needed to care for him”. [F29]

Instilling the appropriate respect for God in the children was reported by six fathers as a way to train their children to know what is good from what is bad and to grow up into responsible adults. These fathers felt accountable to the Almighty God for the life of their children and therefore to ensure they met expectations their day-to-day upbringing was based on biblical principles.

“We are training him according to the word of God. As I earlier stated, whatever the child would become is dependent on we the parents and we are accountable to God. So we train him to know good and bad so he would grow up responsibly”. [F11]

“In training my first child, we sit together and I teach her the scripture and morality, good and bad etc. [F19]

As part of the nurturing skills, some of the fathers (6) also gave account of how they tried to maintain an amicable relationship between their children and themselves so

they would be able to use that as avenues for counselling and advising them when they erred.

“Children are our responsibility. We are to raise them up. As for me, I chat with them as though they are my friends. My first son loves football so we chat about it. He is mostly in Accra so every so often he calls me and tells me what is going on”. [F9]

“I don’t believe in always spanking children. When they do something bad you call them, sit them down so you can talk to them. You can also take them for a stroll and in the course of it draw their attention to their unacceptable behaviour”. [F19]

“I am a person who would not like my children to fear to approach me so I have created a congenial atmosphere in my house that allows for communication. Another important area is their education. Whether you can afford it or not, you must aim at educating your children to a level higher than what you achieved. Besides I try to counsel them where necessary. I have realized that I have the gift of counselling and have been able to successfully counsel other people so I see no reason why I must not let my children benefit. One thing I have come to realize is the fact that the way you handle your child determines how bad they get. If you don’t give them the attention they desire, someone will give it to them and what they might give will not be good for your child so I try to give them whatever they need within my means”. [F28]

The final aspect of nurturing and childcare reported by the fathers was disciplining the children for unacceptable behaviour. Disciplining was seen as the last resort when attempts to advise and counsel have not yielded any appreciable results. Disciplining meant soft spanking.

“Mainly I play with her and educate her such as supporting her in completing her homework. This is what I do also for all the others. In their upbringing I check to find out if they are attentive to the words of advice and direction we give them. If they are not observing them, then they are brought in check. We all have been children before. There are times when they are recalcitrant. So to check that, they are given a few correctional pats or talked to”. [F8]

These roles described by the fathers suggest their active involvement in grooming their SCD children to become socially acceptable and responsible. This implies that such strengths could be used as foundation stones for teaching parents and strengthening them in skills for supportive living and directing their children in choosing appropriate vocations.

Though most of the fathers (28) felt they were doing their best in nurturing their children, three expressed their frustrations for reasons that bordered on lack of cooperation from the mothers of their children who may not necessarily be their present wives. For example, a father withdrew from seeing the daughter in order to ensure his peace of mind. Unfortunately, that was the child with SCD. The father indicated that the strained relationship between the parents had affected the level of attention and nurturing that he was able to give the child. For more than six months he had not had any close contact with the child. His reactions were as follows:

“Presently, I would say because we did not marry, the lady has married and the child lives with them. In the early stages of their marriage, I used to visit her house to see my child and to send support allowance. But over time the lady informed me that my coming there seemed unwelcome by her husband so I should not come but rather she would come routinely to collect the support allowance. So she would call me as and when necessary and agree to meet at a point to collect whatever she needed. Once a while (in a month or more) I would go for the child to spend a night with me. But it is a long while since I have done that in recent times. The reason being that there is a strained relationship between the mother and I. Because we did not marry, she sometimes creates trouble. [...]. She disturbs my peace of mind. I don't want her to come near where I am. She calls me when necessary and I go to see them but not they coming to me. There have been times when she has come to my office and created a scene. She came all the way and insulted me in the midst of my colleagues. I stopped picking the child because at one time, the little girl was able to lead the mother to my house and she again came to create a scene there. For the last 6 months or so I have not brought my child home. But the child knows me and recognizes me as her father who loves her”. [F16].

F 31 also stated:

“My wife does not allow my children to even come to me. The children do not serve me in anyway. You only see them when they are ill and they need money to go to the hospital. Do you think that is a good thing to do?”

Another source of frustration was the fact that some of the children were not living with both parents for various economic and social reasons. Therefore the fathers had to extend their nurturing responsibilities from a distance using appropriate intermediaries, even their older children.

“In bringing up my children, I am most concerned about the food they eat so they will be well nourished. But my 1st wife is not that concerned. Though she attends

education sessions at the hospital, she does not take good care of the SCD child. That child wakes up in the morning, does her own cooking before going to school.

That time the mother would be fast asleep. Because this child is not receiving the best attention she requires, she is not thriving. Just recently she was sick and it was the elder sister who came over to collect some money to take her to the hospital. The mother comes home late from the market and has little interaction with the kids. These were my reasons for wanting to adopt the 2 younger ones but she refused". [F23-forty-nine year old father of 6 children, divorced wife of 4 children and remarried]

These two situations raise concern as to the level of health care maintenance being received by some children with SCD who by virtue of their condition need specialist care both at home and at the health facility to be able to survive the effects of disease.

Conclusions

In summing up, this chapter has given an in-depth understanding of the context of Ghanaian traditional courtship, religion and marriage, childbearing and family division of labour as perceived by thirty-one fathers and nine mothers of children with SCD. Findings on the whole suggest that courtship in the Ghanaian sense is a period in the relationship of a young man and woman when the two who are not formally married engage in a regular and steady relationship which may include sex. This relationship may or may not be known to the woman's parents and is literally described as stealing access to the woman. It is perceived that courtship should translate into eventual marriage. However not all the relationships culminated into marriage, and indeed some ended in pregnancy and child bearing outside of marriage.

To an extent religious beliefs also influenced patterns of courtship and marriage among the fathers interviewed. All of them indicated that they were Christians with varying degrees of commitment. The committed fathers were very cautious in their relationships to avoid going against their teachings and practices. Though counselling

prior to marriage was reported to be common in all the Christian churches, fathers noted that requests for testing were predominant in the Pentecostal denominations of the Christian fraternity. Findings generally suggest the important role that personal beliefs play in determining preparation towards marriage and the extent to which the type of religious denomination one belongs to influences the uptake of screening services such as testing for SCD status. This implies that programmes looking at increasing uptake of screening for sickle cell status could partner with religious organisations in accessing eligible populations.

Traditional marriages were reported to be the most accredited means of having a wife. Fathers interviewed ascribed humble attitudes, modesty, decency and beauty as being some key reasons for marriage. Marriage involved a ceremony where families of the man and woman met to negotiate, agree and accept a package of items that signified and then certified the marriage between a man and woman. Without a traditional marriage, the couple could not engage in a marriage of ordinance. Marriage was also perceived as means for having companionship, support and a stable environment within which to bear and nurture children.

Again findings suggested a laid down traditional procedure towards marriage. This procedure was distinctively set in four stages: courtship, knocking, traditional marriage and civil marriage (optional). This procedure was well known to the fathers, but not all of them adhered to it. Besides, babies were born before or after any of these stages without any reflection on their genetic constitution: a concept generally foreign to them, though it is assumed by genetics authors in Western Countries that it is a

“good thing” for carrier status to be widely known by people in the community before having a child/marriage.

These attitudes of the fathers raise implications for health and social policies intended to encourage people from the stage of young adulthood onwards to know their carrier status in SCD. Such policies would need to take account of the potential (and perhaps unintended) consequences of genetic information in interaction with each of these stages. It would also need to take into consideration appropriate timing for introducing communities to the concept of genetics and its relevance to childbearing and SCD.

Children were perceived as crucial to the survival of every marriage, and as a gift from God. For most of the fathers, marriage without children would be an empty one. Therefore the announcement of pregnancy and childbirth was welcome news to both the man and the wider family. Findings on the symbolic value of children in marriage strongly suggested that children were so important that a couple would rather have a child who had SCD than not to have at all. Three fathers recounted social contexts within which the birth of a child with SCD was highly unwanted, resulting in problems with childcare and support. Though none of them indicated that they disliked children, the circumstances surrounding the pregnancy diminished the interest and enthusiasm with which they received the news of pregnancy and childbirth.

Childbearing brought onto the couple a sense of responsibility that had been defined traditionally by gender. Men claimed they were responsible for spiritual leadership, health, education, clothing, shelter, food and nurturing combined with discipline. The

women were responsible for childcare and housekeeping. The pre-defined traditional gender roles influenced the way fathers related to their wives and children. Some went strictly by the assigned traditional roles whilst others were prepared to compromise in the light of social values, expectations and current changing trends in marital relationships and childcare.

Though most fathers reported they were playing their roles accordingly, there were a few who felt frustrated in the dispensation of their duties as a result of a claimed lack of cooperation from the mother of their children with SCD. Consequently, they played their role by proxy which tended to have its own associated challenges in the presence of strained relationships. It also seemed that SCD care became incorporated into the everyday life of the men without much agitation. The findings suggest there may need to be flexibility in the manner by which SCD programmes help promote paternal involvement in managing SCD at home.

In the next chapter, the researcher describes the lay meanings of health and illness, fathers' perception of SCD as a chronic disease, and the knowledge of SCD acquired through family, parental education sessions and well wishers. The chapter also draws on relationships between fathers' acquired knowledge and their interpretation of the lay meanings ascribed to SCD. An attempt is also made at describing the lay understanding of how SCD is managed in the context of lay perception as a disease of metaphysical causes.

CHAPTER FIVE:

THE SOCIAL MEANINGS OF HEALTH, ILLNESS AND SICKLE CELL DISEASE

In the previous chapter the researcher provided an in-depth description of the context of Ghanaian traditional courtship, religion and marriage, childbearing and family division of labour as perceived by thirty-one fathers and nine mothers of children with SCD. Traditional marriages were reported to be the most accredited means of having a wife and children were perceived as crucial to the survival of every marriage. Several anthropological studies have underscored the importance of child bearing in African societies in general and Ghana in particular (Ebin, 1982; Calnan, 1987; Radley, 1993; Freund and McGuire, 1995; Cornwall, 2001; Geelhoed et al. 2002; Richards, 2002). However, having children is important to the African irrespective of age, marital status educational level or occupation because it proves ones fertility, marks an adult status and creates ties of obligation between people among other factors.

In this chapter, the researcher outlines the lay meanings of health and illness, fathers' perception of SCD as a chronic disease, and the particular manner in which the birth of a child with SCD comprises a deviation from the ideal cultural notion of health. It gives account of the depth of knowledge acquired on SCD through family, parental education sessions and significant others.

The chapter also draws on relationships between fathers' acquired knowledge and their interpretation of the lay meanings ascribed to SCD. These interpretations have

been outlined in the form of lay discourses on SCD. An attempt is also made at describing the lay understanding of how SCD is managed in the context of lay perception as a disease of metaphysical causes.

‘Health a key to progress’, ‘Illness an enemy of humankind’, ‘SCD, blood that sleeps in the blood vessels’: The Social Concept of Health, Illness and SCD

Social scientists have considered lay perspectives on a wide range of chronic illnesses and have contributed immensely to the general understanding of the illness experience through a sociological consideration of disease conditions such as leprosy (Mishler, 1981); rheumatoid arthritis (Bury, 1982); Parkinson’s Disease (Pinder, 1992); cancer (Mathiesen and Stam, 1995); hypertension (Thorogood, 1990, Morgan, 1996) and diabetes (Helman, 2000; Pierce and Armstrong, 1996; Rajaram, 1997). For such authors, the main areas of concern have been in the wider context of beliefs about causes of disease, real and anticipated stigmatisation, biographical disruptions, uncertainty and fear, and the diversity of coping attempts aimed at renegotiating their identities and reconstructing their ‘self’ (Helman, 1985; Corbin and Strauss, 1988; Charmaz, 1991,1994; Mathiesen and Stam, 1995). According to Helman, a variety of lay conceptions of the origin of illness exist. Thus the cause of illness has been variously reported in lay accounts to lie with the patient, the natural world, the social world or the supernatural world. These scientists have also described the variety of lay concepts of what constitute health, illness and chronic illness and related these to their implication for care both at home and in the hospital setting (Myfanwy et al. 1985; Calnan, 1987; Radley, 1993; Freund and McGuire, 1995; Ahmad, 2000).

In the conduct of this study, the author sought to define respondents understanding of health, illness and chronicity as a basis for further understanding what they perceived to be the relationship between their concepts of the terms to SCD.

Meanings of Health and Illness

The following quotation from Berger and Luckmann, (1967), cited in Mishler et al, (1981: 141) sets the tone for the discussion:

“While it is possible to say that man(sic) has nature, it is more significant to say that man constructs his own nature, or more simply that man produces himself.....It is important to emphasise that the relationship between man, the producer, and the social world, his product, is and remains a dialectical one. That is man (not of course in isolation but in his collectivities) and his social world interact with each other”.

Consequently, in describing findings in this section, the author focused on what fathers of children with SCD perceived to be the meaning of health, illness and chronic illness. The implications of their perceptions for care in comparison to the literature will be discussed in Chapter Seven.

With respect to the social meanings of health and illness, all thirty fathers revealed that they had a concept of health expressed singly or as a combination of ‘*a sense of wellbeing*’, ‘*ability to carry out routine activities*’, the ‘*absence of aches and pains in their day to day movements*’, a product of ‘*environmental cleanliness*’ and a ‘*key to progress*’. Another key feature in their descriptions was the attempt to define health as the reverse of illness and vice versa.

Based on the specific accounts of the fathers, the concept of health could be defined within five categories namely health as: *sense of wellbeing; ability to exhibit physical strength, resource for economic endeavour; product of healthy lifestyle and clean environment*. The illness state was also categorised into three. These included illness as a source of: *distraction; erosion of confidence and deviance*.

In health as *a sense of wellbeing*, fathers likened health to the feeling of ‘goodness’ when one can get on with the days work without any hindrance. According to F20, it reflected the absence of disease or infirmity (WHO, 1948) and the harmonisation of all parts of the body into a complete human structure capable of its ‘normal’ function.

“Health is wellness. Someone who does not get ill often is said to be healthy. Illness is anything that prevents you from doing your routine activities. Illness is a distracter in human life. It does not prosper the affected person and is not a desirable situation”. [F20-forty-one year old father of six children, one with SCD]

Health as the *ability to exhibit physical strength* was used in a context of describing the individual’s capacity to display physical fitness. Health was perceived as a conservator of strength and the embodiment of physical ‘peace’ because there is nothing in the body that ‘troubles’ the individual. As implied by F25, health builds the individual rather than *‘pull you down and rip you of your strength’*

“....That is when you don’t have any ailment troubling you and you feel strong. Illness is an enemy of human kind. It destroys, pulls you down and rips you of your strength”. [F25-thirty-eight year old father of four children, one with SCD]

In another vein, health was the *resource for economic endeavour*. As F28 notes, it was an asset for progress that allowed the bearer to go about doing what was perceived as normal duties which may mean earning a living and being able to support the family as a key responsibility of men.

“This seems a difficult question. But I think health is when you are not frequently ill and you can go about your normal duties without any hindrance. Illness is a situation

that retards your progress. Supposing you are a self employed person and for illness you were not able to go to work for a day. You'll loose your revenue and it will affect your business". [F28-forty-one year old father of three girls, the youngest with SCD]

It was obvious here that the traditional role of men as financial resource for the family was an underlying factor to the perceived concept of health. This means that social definition of health is influenced by a complex aggregation of peoples' perception of their social roles and expectations and the degree to which they are able to function as a consequence of the presence or absence of health.

In the concept of health as '*product of healthy lifestyle and clean environment*' good nutrition was the focus of the discourse. F 12 noted that eating good food and keeping a clean environment was a means to preventing disease conditions such as hypertension. Mention was also made of the importance of proper ventilation as a means to good health and the observation of a careful life in adulthood. By implication F12 perceived that lifestyles in childhood and adolescence were not determinants of adult health. This concept leads to again to the notion of defining health within an individual's social purview as well as previous knowledge. F12 obviously defined health by constructing a meaning derived from the medical model of disease causation and relating it to probably his current situation or expectation of health.

"Someone who is able to go about his routines with no trouble is healthy. Someone who eats good food, is clean and tidy, cautious about what he eats if say he has a disease like hypertension, ensuring that he sleeps in a well ventilated room..... You don't have to live as carelessly as you lived when you were younger. I would say illness is occurs when you don't do things that will keep you healthy". [F12- a forty-nine year old father of 3 boys, one with SCD]

Conversely, illness was a deviant concept shunned and deemed unacceptable. The fathers noted that illness was an enemy of human kind, a distracter and a destroyer that took the affected person away from his routine activities. Illness therefore also robbed ones confidence and stigmatised the individual. F21 reported:

“Health is when you can go wherever you want to go and come back without any inhibition. Illness is when you have pain or you are incapacitated in a way that prevents you from doing what you ought to do. You can’t even go out confidently. You are always walking behind walls because you don’t want anyone to see you. That is illness”. [F21-sixty-five year old father of five children, three had SCD with two of them dead]

These accounts were linked again to the fathers’ concept of health derived from the cultural and social construction of their reality of illness. It is possible that the definitions were based on individual experiences of illness and its consequences. This definition represents a ‘truth’ seated in the psychological and emotional determinants of health (Morgan et. al.1985; Helman 2000; Freund and McGuire, 1995).

The meanings fathers ascribe to health and illness offer lessons for understanding the concepts within the Ghanaian socio-cultural context. They represent a body of knowledge that could serve as the foundation for teaching health care workers (HCW) especially nurses, doctors, pharmacists and even social workers in the health delivery system about the social context of health and illness and to promote the application of these concepts in the day to day interactions with patients at all levels of care. They also offer ideas for developing learning tools for helping parents of SCD children explore their feelings about SCD within its steady and illness states.

Meanings of Chronic Illness

Another dimension of illness that the researcher sought to know from the fathers was their understanding of chronicity. In their explanations, they stated that chronicity was associated with an illness that defied cure. One father [F8] described chronic illness as one that has become burdensome because the sufferer has done all that is possible within his means but the disease persists. Generally, all the thirty (30) fathers interviewed explained chronicity in terms of its defiance to cure, persistence, lingering effect and an eventual potential to kill the sufferer. They related chronicity to such common conditions as cited in the literature above such as hypertension, diabetes, cancer, AIDS, tuberculosis and hepatitis and felt convinced that such diseases definitely fitted the description. The following quotations support the assertions.

“You mean chronic? An illness that is a burden. Because you have done all that you can do and still it persists” [F8]

“.....It’s like diabetes and those serious diseases. What makes diabetes chronic? Any disease which takes a long time to treat. A disease with a lingering effect on the body. Any disease which takes more than 2 /3 weeks is chronic.....You see hypertension and diabetes are diseases you can’t cure. It is a continuous situation. You give drugs to relieve symptoms” [F9]

“Erm diseases such as hypertension and diabetes I understand are chronic diseases”. [F12]

“Yes a condition like AIDS is chronic. It is a viral disease”. [F15]

“Chronic illness is one that will eventually kill you. Despite all that you do it will not be cured”. [F20]

“A disease that you cannot treat but stays with you until God calls you to eternity e.g. AIDS, cancer”. [F26]

When it came to the issue of SCD however, there were divergent views. There were those who readily stated that it was a chronic disease and they formed the majority (24) and those in the minority who attempted to defend their stand that SCD was not chronic (7). Of those who readily accepted that SCD was chronic, it was evident that they had had the opportunity to receive factual medical knowledge on the subject and had come to the understanding that it was indeed chronic though with some reservations.

The following were some of the statements made to that effect:

F19: "SCD is as I have learnt is described as recurrent, not curable and from the blood. I have however learnt recently that when the children are born anew, there are certain things that the doctors can do but I am not very sure of this information."

Res: So is SCD chronic?

F19: Erm I think so. Because if you treat it, and it keeps recurring, then it is chronic".

"SCD I will say is chronic though I will not compare it to a disease like AIDS. SCD we have been made to understand cannot be cured in Ghana. But if affected patients conform to treatment guidelines then their quality of life could be improved". [F 20]

"I am not a doctor but I have seen people with these diseases trying to get themselves cured to no avail. Also I think any disease of the blood is also chronic especially those inherited. SCD falls into this group". [F30]

Even these fathers who stated that SCD was chronic tended to distinguish the disease from what they called 'others' such as AIDS. To them SCD as a chronic disease was socially more acceptable to bear than AIDS. Such statements the researcher believes were made as a means to psychologically make SCD more bearable and justifiable than the highly stigmatising disease of AIDS.

The relation of SCD to HIV/AIDS in a system of meaning is important. Both are chronic and blood-related. But SCD is positioned by the men's account in such a way as to distinguish between culpable and non-culpable conditions. Below is a statement from F1 to illustrate this point:

"I would like to say that usually if a recalcitrant child brings home a disease such as HIV/AIDS, it is possible for the parents to feel angry and disappointed with the child but SCD is not like that. Parents cannot blame their children with the disease because the fault is not from the children. Such parents should not neglect their children but rather give off their best to the child". [F1]

It is also possible that the advent of AIDS as a new emerging chronic disease may have influenced the social construction of SCD as less stigmatising. (However, the issue of how and why HIV related illnesses are particularly liable to be constructed as indexing culpability is not the focus of discussion in this thesis) This will be further explored in discussing findings in Chapter Seven.

The culpable nature of SCD and the tendency for the fathers to differentiate it from other chronic diseases (SCD) show the extent to which society is capable of constructing meanings into the causality of diseases and drawing markers for each disease in such a way that the position assigned to the condition determines its degree of graveness and stigmatisation. In this way SCD is positioned in the light of the marker of AIDS. Most often the positioning is determined by a synthesis of social experiences, factual medical knowledge and lay conceptions. These findings suggest the need for SCD education and training programmes for HCWs and families to include models of chronicity and social meanings into their curriculum. This will offer opportunities for further discussing the Ghanaian context of health, illness and

chronicity and the process of social positioning of the different types of chronic diseases and the factors that underlay such positioning. It also raises questions for further research within the Ghanaian socio-cultural context.

Of the few (7) who felt that SCD was not chronic they supported their assertions by the use of terms like *'my child gets sick twice or thrice a year only'*, *'It's a normal disease, you only need routine drugs'*, *'SCD is a blood deficiency: a human deficiency, unlike hypertension and diabetes'*, *'SCD is a blood disease, if one is not careful then he gets it'*.

Two categories of meanings to chronicity could be inferred from the fathers' narratives. They include i) Chronicity as *frequent, continual and complex disease* by comparing it to a communicable disease like malaria and its symptomatology which is described as simple and treatable by some routine drugs such as vitamins and anti-malarials ii) Chronicity as *not related to heredity (unhereditary)*. In their accounts fathers marked SCD as hereditary, perhaps based on exposure to technical medical information thereby justifying its hereditary nature.

By *frequent, continual and complex*, F8 and F11 in their statements put meaning to chronicity in the light of frequency of illness and the complex presenting signs of illness. To them, what they perceive to be malaria because of fever is a simple condition, transient and treatable to an extent that by the time one grows up it could disappear altogether.

"I will not say SCD is chronic because using my daughter as an example, she gets sick only about twice or thrice in a year. I don't perceive that as having a chronic disease. Her main sickness is malaria. That's all. So I don't consider SCD as chronic. It's a normal disease that with regular intake of your routine medication such as folic acid you will just be fine". [F8-forty-one year old father of one with SCD]

“I see SCD as comparable to malaria or isn’t it. That is what I think. Because when I was younger, I was always down with fever and my colleagues would always say I am not strong. But now I am even amazed at the work I am able to do. I do not get sick that often any more. [F11- thirty-seven year old father of one with SCD]”

However fever in SCD could actually be a sign of any form of infection in his child. The father appears not to understand the scientific basis that SCD increases infection rate due to poor functioning of the spleen and therefore the child having malaria could be as a result of low resistance to infection. The endemicity of malaria in a tropical country like Ghana could also be contributing to his meaning. It is worth noting that the case of F8 is different from a majority of the men interviewed in that he was of a middle class status and capable of providing a better quality of care for his child thereby reducing the adverse effect of the disease on his child. These circumstances could explain their concept of chronicity as compared to the medical interpretation.

Chronicity as *not related to heredity (unhereditary)* positioned SCD clearly as a blood disease which they could identify with through technical knowledge gained but to which they still actively struggled to accept within the milieu of lay concepts of the disease. F15 for instance noted:

F15: “I would say SCD is a blood disease. We have been told that when the blood sleeps in the blood vessel then it causes the child to get ill. In terms of whether it is a chronic disease, some say it can be treated whilst others say the problems associated with it will reduce or go away.”

Res: Do you consider it chronic?

F15: Tsmm! To me it is not a chronic disease. It is a common disease that attacks children and somehow cripples them but when you seek the right treatment it can be treated”.

It could further be inferred that this group of respondents, as with the group who indicated that SCD was chronic, had a level of uncertainty in their conviction of the chronic nature of SCD. This was reflected in statements like *‘I see SCD as*

comparable to malaria or isn't it? That is what I think'; 'I will not say SCD is chronic because using my daughter as an example'; 'Well, I don't know whether it qualifies for that but it is a human deficiency'; 'the blood sleeps in the blood vessel'; 'To me it is not a chronic disease. It is a common disease'. These statements showed indications that they have been exposed to competing theories of SCD in popular discourse and also that there was uncertainty about which to believe: the technical medical information, lay beliefs, or ideas that show a complex blend of lay and professional ideas. They sought clarification from the researcher to help resolve these competing theories and the health care available.

The implications of these findings for SCD programmes is in the importance of creating a conducive learning environment within which fathers can explore the competing theories of SCD causality in a bid to arrive at a meaning that helps them to take advantage of the best of out of these theories.

In the ensuing section the researcher further looks fathers' existing knowledge about SCD and how this knowledge impinges on their decisions to marry and have children including those with SCD.

'Swollen feet', 'Tying up aching joints', 'Stuck sperms': Knowledge of SCD and its Meanings for Marriage and Childbirth

The key to facilitating health behaviour change is the understanding of the health beliefs and health knowledge of a particular population. There is also a general assumption in behaviour change communication that providing medical knowledge

about a disease condition, may help in informed decision making (Dennis-Antwi, 2000). With this background knowledge, the researcher sought to know from the thirty-one fathers their prior knowledge about SCD and how, if at all, that influenced their decision to marry and have children. The author believes that such findings could be very instrumental in informing health policy decisions about the best period for carrying out genetic counselling in SCD among would-be- fathers.

Knowledge on SCD

Findings indicated that of the thirty-one fathers, nearly half (14) had prior knowledge of SCD before marrying or having their children with SCD. One of these fathers was a known SC patient. The fathers further stated that their knowledge of SCD ranged from seeing someone with the disease, having read about the disease or received a briefing on it to having lost a child to the disease as depicted in the following statements:

“Actually yes! In fact, Erm, let me go back to history. With my first wife, we had a child apparently with SCD. We were then in Cape Coast. We used to see symptoms such as swollen feet but we did not know it was SCD. Eventually the child died. His condition was complicated by measles and he died” [F12].

“Yes. I had a senior sister I lived with right from infancy who had an SCD child. When she is ill in the night, we used to rush her to the hospital so I had a little knowledge about the disease. Now she is a big girl. She has completed SS and is doing well”. [F18]

“Yes I had heard of it. I had a friend in the US who was sending me pamphlets on some disease conditions of which SCD was one. [.....] I was particularly interested in SCD because I had a nephew who showed symptoms similar to what was described in the literature. He was my sister’s first born and I loved him so much. Unfortunately the boy died. Then I did not know it was SCD. So several years later, it was only when I read the literature that it dawned on me that the child was suffering from SCD. I remember he used to take all sorts of drugs. That time they always said he had ‘ahotutuo’ (very painful recurrent body ache) as we locally call the disease which worsened during cold weather. He always had yellow eyes. I loved him so much” [F16].

Other ways through which the fathers came to know about the disease included living with a family member who had the disease to knowing a school mate who had the

disease. Their knowledge about SCD was a mixture of factual medical knowledge blended with experience, myths and lay conceptions. These were described in their own words as a '*disease that brings lots of pain*' to the affected person; '*during cold weather he develops serious pains and he has to be tied up*'; '*when the couple's blood are incompatible with each other that is when you have such children*'. These statements again reflect how the fathers are able to incorporate technical professional knowledge into their understanding and draw meanings ranging from technically correct, to meanings that leave them vulnerable. For instance, the interpretation of 'blood being incompatible' is a lay reformulation of a one-in-four chance in each pregnancy when both parents are carriers or a re-casting of the concept of rhesus incompatibility, which, though blood-related, is not synonymous with SCD inheritance.

Furthermore, the fathers implied that they were capable of recognising certain signs in their children: swollen feet, severe bodily pain requiring home remedy such as tying up (see Figure Three), cold weather influences, daily intake of lots of drugs, rushing to hospital in the night etc. but did not associate them with SCD until they had the opportunity to learn about it. They were however familiar with '*ahotutuo*' which they used to describe the incessant bone pain experienced during crisis, but there was no association of the other signs or symptoms to the pain in order to generate a syndromic concept of the disease. Two local terminologies '*ahotutuo*' and '*sasaboro*' are used synonymously to imply the painful crises experienced by patients. Some people differentiate the two by employing the category of age to qualify '*ahotutuo*' as occurring in younger people whilst '*sasaboro*' occurs in older people and related

more to arthritis or rheumatism. In this study, fathers often used '*ahotutuo*' to express their children's experiences of SCD.

The concept of '*has to be tied up*' within the socio-cultural context of Ashanti Region where the researcher worked as a Health Education and Counselling Coordinator for SCD is a home remedy for painful crisis within communities where the medical concept of SCD is not well-established and where, therefore, there is reliance on local approaches to relieve pain. Consequently patients in painful crisis cry out to be tied at the points of intense pain in order to provide transient numbness and dulling of the pain (see Figure Four). This procedure is not considered as punishment or an abuse of human rights within such localities but a strategy in the absence of no better resource to reduce pain and suffering. Unfortunately this practice has its own associated medical complications as tying up further complicates blood flow through the affected parts thereby resulting in further sickling, poor localised circulation and the possibilities both of bone infection (osteomyelitis) and of neuropathy.

Figure Four:

Concept of being tied-up and Placement of Weights on Affected area to Reduce Pain

Figure 4A. Tying Up With Ropes



Figure 4B: Placement of weights on affected area to reduce pain

The existing knowledge as well as home remedies on SCD that fathers have prior to their introduction to the medical model of SCD is important in understanding the basis for some of the complications that patients may present at SCC for treatment. They also provide lay knowledge that is relevant to the training of HCWs in haemoglobinopathies in Ghana.

On prior knowledge, a particular mention is made here of F9, a forty-nine year old father of four children - the eldest with SCD - who based on his pre-existing knowledge of SCD, took the initiative to check his blood and that of his would-be-wife for trait in the UK where had met and courted. (They actually knew each other in Ghana but had come their separate ways to the UK. They however met in London where they began courting each other). The results of these tests indicated that he was AS and the bride to be was AA and that they could go ahead to marry. This they did and their first child turned out to have SCD-S β^0 thalassaemia. This finding was a big and disappointing shock to the family. The pain he felt at this experience was, the author felt, reflected in his entire discourse during the interview, though he masked this to a large extent with his strong religious belief in God. This is what he had to say on knowledge about SCD.

“Yes as I earlier indicated. I knew I was AS so we checked my wife’s and this was in London. We were cocksure she was AA. So having a child with SCD is a real shock to us. We did check and were damn sure. The thalassaemia thing is new to us. I had heard about the disease but not this one.

My Aunt had lost a child to the disease when we were kids and it was a painful experience for us all so I was particular about avoiding it. When I saw that my wife was AA, I was pleased. But I remember the doctor told her that when she gets pregnant she should show it to a doctor. And we did. We did not think of SCD until we had the baby and he started showing signs of ill-health”. [...]. I have a strong feeling that if our health system could be more responsible in the laboratory investigations they carry out and these investigations are highly accurate that will solve a lot of the health problems we have here. Unfortunately laboratory test are not given the serious attention they deserve”.

It could be inferred from the statement of F9 that due to his previous experience with the disease, he was particularly committed to avoiding it in his family. However, the inability of the health system then in London to help him detect trait status in his wife was a bitter experience and for which he blamed those inefficiencies for having a child with SCD; being disappointed in a system in a country that is internationally recognised as having one of the best health care structures.

The partial application of technical knowledge by the health professionals in London themselves is important because quite frequently lay people are blamed for their ignorance in not taking on technical knowledge given to them by health professionals or their fecklessness in not acting upon technical knowledge in ways the health professionals deem to be rational. And yet health professionals are fallible as in this instance. What this suggests, on the one hand, is that more humility is required by health professionals about the tentative state of their technical knowledge, and on the other hand, more respect is due to lay beliefs which may in some instances be referring to completely different domains of experience and which technical science could not, even in principle, have answers for. One may however argue that since SCD is a condition associated with ethnic minorities in the UK, it is possible that the HCW were not well informed to assist in proper diagnosis.

This raises the implications for the importance of training HCW on techniques for sensitive diagnosis for SCD in countries where there are affected populations. This is even more challenging in a the Western world especially in the UK and USA where migration due to slave trade, economic reasons and political conflicts have resulted in a multi-ethnic and multi-racial population thereby making it difficult to identify at risk

populations for screening (Dyson, 2005). This statement does not exclude endemic countries such as Ghana where sensitive testing is sometimes lacking at the district and sub-district levels of health care, resulting in patients undergoing solubility testing rather than more precise tests such as haemoglobin electrophoresis, resulting in similar situations to that of F9. Advocacy of better services for SCD care should therefore highlight on the application of effective testing mechanisms to exclude false negatives and false positives.

Still on knowledge on SCD, seventeen fathers knew nothing about the disease though they had heard it being mentioned in passing by family or friends or seen someone in episodic pain but did not know what was actually happening, as one fifty-three year old father of four children explained:

“No I knew nothing about it though I had seen someone with pain ‘ahotutuo’, I did not understand the cause of the disease or what it meant”. [F 17]

Another sixty-five year old father of five children also stated:

“No I had never heard of SCD. I had heard of ‘ahotutuo’- rheumatism but not this one”. [F21]

Their statements indicated that they had no idea what it meant to have SCD and how one came to have it. What they had heard about the disease was superficial and did not offer them any level of understanding capable of influencing their decision to marry the love of their heart.

It is interesting to note that F16 (above) sees ‘ahotutuo’ as merely the lay name for SCD, whereas F21 sees SCD and ‘ahotutuo’ as separate entities. This difference as explained earlier is due to previous experience with the disease coupled with technical medical knowledge that provides a syndromic approach to explaining the disease.

Without that background, society tends to perceive 'ahotutuo' as strictly bone pain. There is a parallel here with malevolent 'ogbanje' (Nzewi, 2000): where some perceive it to be SCD, whilst others see it as encapsulating other diseases as well as SCD.

Knowledge on SCD and marriage

Asked whether their previous knowledge and understanding of the disease would have influenced their decision to marry, half of the fathers (15) stated categorically that they would not marry and that they would have called off the relationship whilst of the remaining sixteen, five would have sought for medical intervention to remove the trait from their blood to enable them marry. They made such comments as: *'I would have sought for medical help to combat the disease whilst my wife was pregnant; 'I would have tested, sought counselling before deciding on how to remove the trait'; 'I would have devised a strategy for preventing it'; 'I would test and get rid of the trait before marriage'*. These statements indicate the understanding of these fathers that it is possible to eradicate a trait situation. This signifies their limited technical appreciation of the genetics of SCD.

Furthermore, another nine would have proceeded to marry anyway. A father said he would decide to marry depending on how the would-be wife felt about nursing a child with SCD. On this issue, F9 did not give a direct answer as to what he would do because to him, it had already happened and there was no looking back on what he would have done.

He said:

“Personally, I don’t look back. I don’t like looking back at past things. I like to move forward seeing how best to care for my wife and children. After all, life is a challenge. Nothing is as easy as it may seem to be”

In this statement F9 presents a scenario where it is perceived as irrelevant to consider what he would have done. With a history of disappointment from a health system he trusted to help him prevent the occurrence of SCD in his family of procreation, it is possible that he felt there was no need in trusting the system anymore. Therefore there was no point in looking back. Another plausible explanation is that, F9 is a man from a rich family of timber merchants. In a society where the rich are held in high esteem, and regarded as being in control of their situations, he would feel defeated to acknowledge contemplation of withdrawal from marriage or otherwise.

Overall, the two groups of fathers (those who knew and those who did not know about SCD) went into marriage and began having children with their pre-existing knowledge they had gained on SCD. The implications of their actions for SCD programming are two-fold. Of those who knew about SCD, it is obvious that the availability of reliable, well publicised and sensitive testing services would have helped them to make informed decisions. The second implication is the relevance of genetic counselling to serve as a source of reliable genetic information on SCD to enable would-be-couples to construct meaning into the ‘permanent’ nature of genetic constitution: permanent in the sense that genetic modification procedures are largely unavailable in Africa and even if they were would be generally unaffordable.

Of the 17 fathers who knew nothing about SCD, being told that their child had SCD did not mean much to them initially. Eight commented that their appreciation of what

SCD really is was only obtained through actually having a child and caring for that child. This is how one father expressed it.

“Oh I knew about it but not that in-depth in that I did not appreciate the extent of pain they could experience. Therefore I do feel bothered to see my son in pain. It is a bit worrisome. So I would pray for his speedy recovery. Apart from that I would say I knew about the disease”. [F29]

The 15 fathers who categorically indicated that they would not marry if both their would-be-wives and themselves carried the sickle cell trait, further explained that making that decision would not be that easy when they have children and more especially a child with SCD:

“In that situation you are not married yet so it is easy to make a decision but when you have married the person and had 3 issues with the 3rd having disease, it becomes a different matter. Children are given by God so if he has given we’ve got to take it” (F2).

“If I knew that my partner and I were both AS, I would not have stayed in the relationship to produce a child” (F3).

“As I said earlier, if I had known we were both positive I would not have gone ahead with a marriage to even produce a child.” [F14]

Though these fathers expressed feelings of not marrying if they knew their trait status, one should bear in mind what people say and what people do is different: they may say they would not have gone ahead, but some may actually have done so even though they believe it may not be the technically correct decision to make. Decision-making in the choice of partner may be influenced by a multiplicity of social factors and not by sickle cell status alone.

A father in whom the presence of a SCD child during courtship was enough reason not to proceed with marriage, despite the fact that he loved the woman, describes another dimension of a decision not to marry. To him, why should he continue to

‘produce’ SCD children when it is possible for them to break the relationship for each of them to look for a new partner? He expressed his views thus:

“I was sad when I got to know my child had SCD. I am still in a relationship with the mother because the doctor told me that though it is lawful for me to decide to break the relationship, the time is not ripe” [F3].

A different side to a decision not to marry in the presence of SCD during courtship was the issue of ‘love gone sour’ rather than having a child with SCD. A father made the following comment to that effect.

Res: May I know whether your decision not to marry the mother of your SCD child stemmed from SCD?

F16: Oh no. it was because we were incompatible. We seemed to disagree on a lot of things. Though I knew it would be difficult to take care of a child with SCD, I think that if at the time she was born, there was a strong bond of love between her mother and I, we may still have gone ahead to marry. But that was not the case. We are just incompatible”.

These varied reasons reported by fathers as to why they would marry or not marry their partners in the face of existing knowledge about SCD suggest the need for a diversified programme of counselling for couples who desire to seek genetic counselling services before marriage in Ghana. Such services should be culturally sensitive to the needs of a particular couple within the existing socio-cultural environment.

Knowledge of SCD and Childbirth

Once married, all fathers interviewed stated that their knowledge of SCD would not prevent them from having children. They reported that a childless marriage was unacceptable to the Ghanaian society because childbearing was one of the key reasons for marriage. They therefore had a duty to meet societal expectation and to continue their lineage. Deciding not to have children in marriage was unthinkable to them

especially if they did not have any previous children. It meant “*Letting your sperms get stuck in your waist*”. Even if they had children, their wives would desire a child of that particular union. Below are some of the arguments they put forth in this respect.

“It will be difficult to decide not to have children. We live in a family and we belong to a society. People will talk and make all sorts of nasty comments. The woman will be the first to be accused “ Why have you decided to stay with a woman who cannot bear you children? All your viable sperms will be stuck in your waist”. So it is difficult to make a decision not to bear children. Pressure from society is unbearable” [F30]

“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]

These arguments support their earlier perception about the symbolic value of children discussed in Chapter Four and give credence to their conviction that they would rather have a child with SCD than not to have children at all. However, in the account of four of the fathers, and one of the mothers, the presence of SCD in the marriage was a reason for them to review their earlier decisions about the size of their family.

“Or if we married at all we would have fewer children. Definitely we will have children”. [F17]

These choices made in the presence of SCD in the family by respondents have been reported in the literature to reflect a situation of biographical disruptions (Bury, 1982). Although the majority of fathers expressed the view that, had they known they were part of a carrier couple, they would not have proceeded to marry and have children with the mother of their SCD child, the stage of formal marriage was reported to alter this outlook. All the thirty-one fathers referred to the cultural imperative to have children, or that remaining childless once married was not an acceptable situation within the Ghanaian society.

Childlessness would then have constituted an unacceptable disruption to their biographical trajectory through life: a situation that the researcher, to further develop Bury's notion of biographical disruption, calls 'procreative disruption'. The fathers' feeling that they would have proceeded to build a family, even with the likelihood that a child could have SCD as proved to be the case, suggest that this would have necessitated a reconstruction of meanings attributed to SCD. This required an adaptation to any outsider status or social isolation accorded to the family by virtue of the presence of an SCD child, and the harnessing of available resources to renegotiate a new self to validate oneself through meaningful association with others and to re-establish a stable sense of coherence and order.

'Of sudden onset', 'Time consuming' and 'Challenging': Learning to understand SCD after childbirth

Public and parental education is an inseparable component to most screening programmes for genetic conditions (Lappé et al, 1972). Such community education serves to provide basic medical factual knowledge, demystify the condition in the milieu of socio-cultural beliefs, promote the desirability of neonatal screening and enable parents to accept the results of testing (Hill, 1994). In Kumasi, Ghana, where the newborn screening for SCD programme started in 1995, and which formed the setting for this study, a similar structure was set up to create the opportunity for parents with children diagnosed to have SCD to learn more about the disease.

The knowledge received was expected to help them provide optimal care at home for their children and to guide them in decision-making in case of emergencies, among

other reasons. Consequently, as part of this study to determine the social meanings of SCD among fathers, the researcher determined what new knowledge fathers had acquired to either enhance pre-existing knowledge (before they married or had SCD children) or to clarify any social conceptions .

Learning through Observation of the SCD Child after Childbirth

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 at what instance, 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 work out what they thought worked for them in times of their children’s illness. A majority (21) of the fathers acquired such knowledge through family interactions and care-giving negotiations between their wives and themselves in their daily interactions. A forty-three year old father of four children stated:

“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]

Another forty-nine year old father of three said:

“Let me use my son as an example. He has 2 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]

For F17, a fifty-six year old father of four, SCD is a time consuming condition that requires a parent to be very devoted to the child especially in times of illness, which often occurred suddenly. He had also noted that delay in seeking medical care resulted in complications requiring complex interventions such as blood transfusions. He stated his experiences as follows:

“The experience I have had with SCD shows that as a parent you will need to have a lot of time for such a child. It does not matter that the child wakes up feeling well. He could develop illness any point in time in the day. And when that happens it seems there is nothing that the lay person will do to alleviate the suffering, no Paracetamol, anti malarial or other will help. The ultimate is to send him to the hospital. Sometimes he goes off to play returns home and in a short time he will start complaining. You may decide to treat at home, by the 3rd day after unsuccessful management, you get to the hospital only to be told your child needs to be transfused with blood” [F17]

Though most learnt from their wives to care for their SCD children, there were two fathers who had very little opportunity, if any, to learn about the disease and how best to care for their SCD children. One father attributed it to the nature of his work as a long distance driver, whilst the other said he had no-one to teach him and that what he knew he got from caring for his three children with SCD, two of whom are dead leaving the first child now over thirty years. This implies that with thirty years of caring for a child with SCD, he had had no formal opportunity to learn about SCD from specialist health workers. In their statements, it was obvious that fathers still had a lot of unanswered questions as indicated below. However it is not clear why they did not make any effort to seek out factual explanations to their questions though they were aware of a Sickle Cell Clinic and had allowed their wives to benefit from it.

F23: “We had a child even before we married. My previous wife could not give me a child so children were very important to me. You see I have never understood why this child of mine had SCD. All the others are fine and healthy. I have been thinking that if anything at all it should have been our 1st child.

Res: So have you understood why you have a child now?

F23: Erm for me I have given it to God. If I have 6 children and one is not well. It is okay. After all you can't get everything to be fully okay. There are bound to be problems. What I pray for is that God will give me the grace to work and care for this child".

Apart from learning about SCD through family interactions, the remaining ten fathers who had been very active in attending the sickle cell clinic (SCC) acquired a lot of knowledge through their contacts with the specialist health workers and the support group. They testified that through these contacts with formal health services they knew what to do for their children when in a steady state and when ill. F13 had this to say:

"When we had our son diagnosed, we started attending clinic and through education we have been thought to know what to do. When the child has a fever we are to give Paracetamol, He needs to take lots of water everyday so he will be well. When he is ill say with crisis we should bring him to the clinic". [F13]

In a not dissimilar vein, F4, F9, F17 gave their accounts as follows:

"Learning about the disease has helped me develop a positive attitude. It challenged me to test my blood and that of my wife to confirm that we were traits. This has even led me to take up an ambassadorial role to share the knowledge I have gained with the youth in my village. I urge them to check their blood before marrying. I have some joy in being able to do this. This is why I am so active in the Association work. I have been able to identify a number of children in my village and brought them to the SCC". [F4]

F9: "What would I say? What I can say is that every experience is something that makes you a better person. Once you come across these things, you lead a sober life. The experiences make you more mature and you try to do your best as much as possible.

Res: So apart from the experience how else have you gained knowledge?

F9: Well when we send the child to the doctor, we get information from him on how to go about supporting the boy."

"My profound thanks go to the Association meeting at KATH. Their teachings have been of tremendous help in caring for this child. Without that I don't think our son would have been alive today. Whenever I go for meetings I go with the boy so he hears the teachings directly and he abides by them instead of me telling him because if I do he will not listen. This has been very beneficial to us" [F17]

In comparing the reports of the 21 fathers who did not have much interaction with the SCC with the 10 who had, it can be deduced that the level of confidence in childcare

was greater in those who had had regular contact with the clinic and support group. Furthermore, they exhibited a positive attitude and were willing to identify other affected families and direct them to the clinic. They perceived that their interactions with the support group (Sickle Cell Association) had been a very important and significant determinant in their current outlook on SCD. Though two-thirds of the fathers had gained most of their experience in childcare through observation and experience in dealing with the illness state, there was a level of uncertainty in their perceived lay expertise and they sought answers to questions that had baffled them as they shared their stories with the researcher: an action that suggests a paternal inclination towards a one-on-one interaction in counselling and education.

This implies those education sessions that target fathers through one-on-one interactions would be very beneficial to fathers. Again it was obvious that a majority of the fathers receive minimal or no formal education on their children's condition. Most of the educational benefits derived from direct interaction with health professional falls to their wives who are the regular companions to their children at the SCC. These findings suggest the need for an organised programme of parental education involving *both* parents and designed in such a way as to offer opportunities for fathers to fully participate, so that their observational and practical experiences could be strengthened with the factual medical knowledge. It is envisaged that such a blend will help in a better amalgamation of supportive social and medical knowledge that enhances lay expertise in the care of chronically ill persons such as sickle cell patients.

To better understand how social knowledge on SCD affect the meanings fathers attach to SCD, it is important to gain an insight into what the existing social and if possible religious beliefs are. In the next section, the researcher explores these beliefs and the extent of their influence on the meanings fathers attach to their children being born with SCD. It goes on to draw out the implications of this for paternal care.

‘A bought disease’, ‘A financial drain’ and ‘Cause for early death’: Social Beliefs on SCD and their Implications for Paternal Care

In the literature review the researcher argued that by the nature of SCD as a chronic disease, society positions it as an abnormal condition and thereby legitimises society’s desire to explain and understand its manifestations through a compendium of lay concepts. Moreover, the first section of this chapter has outlined fathers’ perceptions about health, illness and chronic illness and how they classify SCD based on the extent of individual social interactions and medical knowledge received on the disease. These perceptions, however, are not likely to entirely override the variety of names and longstanding lay categories ascribed to SCD in influencing the social meanings fathers ultimately attach to the disease. In order to systematically document some of these lay meanings, (many of which the researcher was herself already familiar with by virtue of her role in being the Education and Counselling Officer for the Newborn SCD Screening Programme in Kumasi for twelve years) the researcher interviewed the mothers, a group of specialist health workers and the fathers. Findings of the interviews are discussed in this section under six main discourses.

SCD: A 'bought' disease

By the accounts of the respondents, laypeople in Ghanaian society perceive SCD as a form of rheumatism characterised by an incessant gnawing pain they literally call 'ahotutuo'-painful body or 'sasaboro'. Commonly, the respondents noted that parents were not directly associated with being the cause of birth of a SCD child.

Genetic causes were scarcely considered as an option even in the face of a family history of members with similar disease presentations. Metaphysical causes were mainly ascribed and explained as a family curse. Fathers and mothers of SCD children were often inundated with unsolicited explanations as to why their children had SCD. These explanations were typically offered by friends, family members and acquaintances.

The initiation of such explanations was often related to the observance of a difference in the physical appearance of the child or frequent parental visits to the hospital. According to the respondents, a typical explanation to the cause of SCD is the belief that it is a 'bought' disease and that the child has been cursed. This categorisation places it under a spiritual or metaphysical cause where witches and spirit mediums (*juju*) are believed to have purchased the disease and inflicted it upon the family through the birth of the child. By this infliction, the power responsible is supposed to receive a form of satisfaction or gratification for performing that act. In the interviews and focus group discussions, these beliefs were expressed as follows:

"Commonly SCD is perceived as a spiritual disease – "Ntɔ yareɛ". A disease that your enemy buys spiritually and implants in your child to result in your downfall so you can never prosper [M5]".

"They perceive it as a "bought disease – Ntɔ yareɛ". In such situation, the old lady in the house or someone who has a strained relationship with the couple could be accused of being the source of the child's ailment. 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].

I have also been told that this is a demonic disease. When you have such a child, you need to pray a lot [M1].

“That the disease has a demonic cause. It is incurable,etc. They say that because they have observed these children get so sick often then die over time” [F13]

The majority of people believe that it is ‘Ntɔ yareɛ’ [F17]

A frightening dimension to the lay perspectives on the cause of SCD reported by the respondents was the assertion that the child himself could be accused of being the cause of his predicament; a situation which was reported to lead to child neglect and abuse if the parents accept and believe in such social discourses. They commented that patients with chronic leg ulcers and chronic splenomegaly (see Figure Five) were often the victims of such discourses. They stated that as society cannot explain why one could have such chronic conditions, a condition defying all treatment for several years of their lives, the best underlying cause would be the metaphysical and for that matter the patient himself. The statement below reported by respondents confirms this assertion:

“They sometimes say the child is a demon or a witch and the problem the child goes through is self inflicting” [F4].

“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).

SCD: The cause of early death – I’ll die today, I’ll die tomorrow

Building upon the earlier discourse of SCD being a ‘bought’ disease, the researcher explored another lay perspective being that of early death in a family mentioned by F30. In response, respondents gave several accounts of lay descriptions of the disease as the cause of sudden death among patients. They noted that it was common for them

to be informed of someone who had the disease and died suddenly. In their statements, they commented that SCD patients are perceived as people who like getting sick – ‘wope yaree dodo’; a statement which blamed the patient again for being ill.

“Literally, I think not many people know this disease. They often blame the child as “like getting sick- ‘wope yaree dodo’. This is what I know. They don’t attribute it to the father” [F21].

Besides their frequent illness, such patients were perceived to die young. It was not uncommon for parents to be informed of age limits within which such children die thereby generating heightened fear and expectation of death among couples whenever the child is ill.

“Some say if you are SS, you will not live beyond 25yrs. You know sometimes these things happen in reality and that is why they say that. You will notice that such an affected person is looking very pale. Overtime, you will hear he is dead. I suppose these are a few of what I have heard. ”. [F11]

They added that due to such statements, it is possible for parents to live in a cycle of fear and uncertainty as to when the ‘death’ is going to occur to the extent that the best way they could deal with the situation is to psychologically persuade themselves that the child is not one who has come to live but that of one passing through life only briefly. The lay terminologies given to describe this phenomenon include ‘onye kye ba’ meaning he does not look like one who would live or ‘Enε mewu: Okyena me wu’ meaning I can die today, I can die tomorrow. The respondents attest to evidence of the currency of such lay concepts through the following statements:

Well some say such children don’t live long and will not be helpful to the family, as I have already said, so they neglect the child waiting for it to die. They see it as a spiritual disease. [F18]

“They also say that he is not a child who would live long (Onye kye ba)”. [F4]

“I had heard that such children die by 15 years of age and a lot of other things so I was really upset” (M5).

“Most people say that such children do not live for long (wonye kyeba). I remember there was a young person in my church who died from SCD. Most of the comments

from people were the same that they don't live long. Because of this belief there are people who may decide that they will not bother to invest in such a child because he will die anyway". [F19]

"I often hear them say that such children do not live long. And they will give you several instances of people who had had their children die from this condition. If you are a parent and you allow yourself to listen to such gossip, you will not have the urge to care for your child." (F4)

"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)

From the above statements it could further be discerned that lay discourses on SCD categorise patients as people belonging to the phenomenon of social death, a concept in which carers believe that their chronically-ill dependents are as good as dead. This situation leads some parents to ignore such children, discounting them as non-existent in social terms and thus wait patiently for the day of biological death. In an interview with one father, he narrated a case in which a particular child had been abandoned by the parents due to such conviction.

"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 by informing the mother [F3-a thirty year old single father with an SCD child. He has decided not to marry partner to avoid more children with SCD].

Other contributions on the concept of social death include the following:

"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 to not go beyond 25 years of age" [F5- fifty three year old father of 2 children with SCD. 1 dead]

"They say they don't live long. I remember a lawyer friend told me such children don't last beyond 15 yrs. Others even give lesser years. When my daughter died at 39 months, I believed what people said. But when my first son who also has the disease was still growing my thinking became divided but with his desire to learn, I just went on caring and observing. Death was the main comments people gave about the disease". [F22- a seventy-year old father of 16 children 3 with SCD, two of them dead]

It is arguable from these narratives that parental reactions to their children with SCD depend on the extent to which they regard the lay interpretations of the outcome of SCD as credible. Parents who perceive what they hear as mere gossips are more likely to ignore them and care for their children to the best of their ability.

Interestingly and sadly, two fathers (F16 and F4) described a major concern which was not about death but what they described as ‘ugly and unsightly appearance’. To F 16, if death will take his daughter who has SCD, that child must go in a decent and attractive manner and not when the disease has contorted and delayed the growth of the child. So that when compared to children of the same age, the child looks smallish with yellow eyes and protruding tummy – ‘*Woayε ndwedwendwedwe*’ literally meaning stunted in growth and likened to the growing style of sugar-cane in the knotted or segmented form (see Figure Six). This is a description he gives to the delay in growth of SCD patients as reported in the medical literature (Embury et al, 1994).

In his own words he said:

F16: Most people say if you have SCD, you do not live for long because of the way the disease presents itself. But I believe it is possible to also live long. What bothers me most is the fact that they look ugly and unsightly. If the person has to die but dies quietly without the ugly appearance, I find that more tolerable than for the disease to destroy your appearance and then kill you again. You deform and then die. It is a bother to me. That bothers me a lot.

Res: What do you mean by deform?

F16: The child looks lanky, with a big protruding stomach and unable to put on weight”.

F4 stated:

“Poor physical development is common among SCD patients in the villages who do not have access to care as we do. Such children look neglected and awkward ‘Woayε ndwedwendwedwe’ in their growth and do not look normal at all”.

On the whole, these interpretations, which appear to be applied equally to both boys and girls, are of social importance to child care and social development in general as they again influence and perpetuate the negative constructions and reconstructions of SCD by laypeople. It is possible that certain mediating factors are responsible for the variety in parental reactions to SCD in their children.

Figure Five: An SCD Child with Chronic Splenomegaly literally explained as the presence of a “*demonic pot*” in abdomen



Figure Six: Sixteen Year old Patient looking smaller for age and size
- 'Woayε ndwedwendwedwe'



In the next section, the researcher reports on yet another lay discourse about SCD reported by respondents which is the result of the formation of lay views within a particular socio-economic environment – sickle cell as a financial drain.

SCD: A financial drain - “Money will finish; SCD is the beginning of your downfall”

In Chapter Two, the researcher made mention of the fact that health care in Ghana is mainly financed by direct fee payments by the patient and that there is a current policy aimed at getting every Ghanaian to belong to a national health insurance scheme. Currently, only about 2% of the population have been registered (GHIC, 2005). Though the Government subsidises health care generally, the cost that is assigned to health care seekers is beyond the means of a majority of the population, thereby making health care financially inaccessible. These observations were alluded to in the interactions with respondents as a key factor underlying some of the lay perceptions of SCD. Such perceptions pointed to the financial implications of caring for SCD patients and continued to reflect the belief that as a bought disease, the enemy uses the illness to drain all the financial resources of the couple thereby rendering them poor and an object of social ridicule. They reported that patients are often called by nicknames such as “*Sika be sa*” meaning ‘*money will finish*’. Some of the narratives were as follows:

“They call my child ‘Sika be sa’ meaning ‘money will finish’ because of the disease” [F5].

“Because of these children’s illness even when I get someone kind enough to give me a loan to trade with, before long, I am unable to account for the money. I think about my children a lot and their future. If they were healthy, it would have been possible for me to travel abroad but now I can’t. Their illness is a problem for me” [M8 – Mother of 3 SCD children].

“My main concern has been working to save so that I can afford the cost of care when she is ill” (F2).

“Truly, cost of care is a major burden to parents. There are times that we shed tears for lack of money to buy drugs for the sick child. I remember one day when this grand child was ill, we were given a prescription and we could not buy the drug. My daughter really cried that night. Her husband had travelled and my other children at that point in time could not come to her immediate rescue” (M9).

“We have been selling our personal effects to break even. I am a person who finds it very difficult to approach someone for help. It is said in our language that “It is the man who swallows the bitter pill”. So when the situation arises I device a means out” (F4).

“As parents we spend so much money on drugs but the child keeps on deforming and then dies. That bothers me a lot”. [F16]

“The general perception is that giving birth to such a child is the beginning of your downfall because all your money will be spent on him” [F30]

Arguably, society had good reasons for calling such a child by that name in that the parents interviewed alleged that their children often got sick as soon as it became apparent that they had earned some money that they could put to ‘better’ use other than pay for hospital bills. Second, the cost of care made parents pre-occupied with working to save so that in case of an emergency illness, they would be in the position to pay for the cost of care. Third, parents had a feeling of being non-achievers when compared to their colleagues because they used all their money to care for their SCD child, leaving next to nothing for other social responsibilities. Parents gave vivid descriptions of their experiences with the financial aspects of their childcare some of which raise important implications for re-thinking the health care system in Ghana to ensure equity of care. It is possible that such parental experiences with SCD have, over time, contributed to what is perceived as social stigma for SCD.

SCD as a Social Stigma

Sickle cell disease can be likened in some way to Parkinson's Disease in that its presence in affected persons raise what is termed as a problem of shame by Nijhof (1995). According to Nijhof, such diseases assume a rule-breaking character resulting in a feeling of shame when in public because their appearance and behaviour are not the norm as perceived by society. Stigma is a discrediting attribute that was a common feature reported by the respondents in this study. With a history of lay perception as a disease of supernatural causes, short life span and a financial drain, it was logical for society to stigmatise SCD in a manner comparable to leprosy and tuberculosis (Mishler, 1981). Stigmatisation as described by respondents fell in two main categories: namely the stigma of being a child with SCD, and what Goffman (1963) has called the "courtesy stigma"- that of being a parent of an SCD child. The following are some insightful recollections from respondents as to why a SCD child may be stigmatised by friends:

"Some will make this remark "Hey stand aside you sick person (yarefoɔ)". The SCD patient is just not counted among the living. You are considered a temporary human being. You can leave at any time". [F6]

"They believe SCD is infectious. So when you are labelled as having SCD, nobody wants to come near you. You are labelled as one near death. Even when children are playing, they would sideline the one with SCD because they perceive that he is not strong enough to play or he could infect others with his condition. That is the main reason why parents deny SCD and keep it a secret" [Group of Specialist Health Workers].

"Must I allow my child to eat with this child who is always sick?" [Comment made by rival of M2. M2 is the first of 3 wives].

As a consequence of such attitudes, parents of non-SCD children would often warn their children to be very cautious of playing with friends who are known SCD patients to avoid any problems, thereby leading to a gradual alienation of that child. This alienation raises

psychological concerns for the growing child who begins to realise (s)he is different and unaccepted by peers.

Among parents of SCD children, it was common occurrence to disclose that their child had SCD to only a select group of people who were close family members, teachers, co-tenants, employers, colleagues who had such children or friends who they felt could be of tremendous support to them. Fourteen fathers indicated such disclosure. The only reason why they shared the diagnosis was to ensure proper care of these children in their absence or to seek for material or moral support. The following statements attest to this assertion.

“I was a worker and needed to get permission from time to time to attend support group meeting so I had to tell my managers so I can get time off to attend meetings and clinic”. [F20]

“Oh! I shared it with those I know who have had such children. I know of a paternal relative who has the disease and is far grown now. I told my siblings and my parents for support. I remember an occasion when she needed to be transfused with blood and I had been hospitalized due to an accident. It was my brother who donated blood. Besides because the family knows she is often not well, she is the one they commonly enquire about”. [F23]

In contrast, seventeen fathers indicated their reluctance to share the diagnosis of their SCD children. This they claimed stemmed from their belief that there was no point in broadcasting that their children had SCD because society tended to make discouraging comments as indicated by the above discourses.

“F23: Oh no! We did not tell anybody. That was the first time I got to know what is SS. My wife and I have taken care of our son all this while. Why would you want everyone to know your son has a disease? If he is not well we just say we are taking him to the hospital. That’s all.

Res: Why did you not tell anyone?

F23: Oh! As for sickness, everyone does get sick at one time or the other. SCD I am certain exist in all families. So if your child is ill then you broadcast it for everyone to

hear? Illness is illness. Some people may have worse diseases than SCD so why broadcast mine”. [F23]

“I have not told anyone per se because if you share it and you are not strong minded they will discourage you so I prefer to be reserved about that. Even if you tell them, they will have no part to play in it. I have not even told my parents because I think it is unnecessary. But the people in this house who are my wife’s family know about the situation. My wife also informed her teachers at school so they would understand her situation in relation to her academic output. We became really quiet when the news came. Quiet because in Ghana, you know people place stigma on certain diseases of which SCD is one. Mentioning that even your child is SS makes people look at you differently”. [F28]

The group of health workers interviewed reported circumstances when parents, upon receipt of medical diagnosis of SCD in their newborns, had denied the diagnosis and refused to report to hospital until the child showed signs of serious illness. The denial and refusal to identify with SCD were explained by the existing social beliefs and attitudes to SCD in Ghana. The position of denial was assumed as a protective measure against the evil forces and also as a declaration of one’s faith in that by not accepting the bad news, one psychologically repels the unwanted omen from residing in the child as explained by a mother, fathers and 2 health workers.

“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).

“Traditionally, SCD is perceived as a bad omen. No one will be prepared to accept that it is in his family”. (F5)

“Because they believe that if they accept what you the HW are telling them then it shall be. But if they deny or reject it then the child is not likely to suffer the disease. It borders on issue of faith”. (HW)

“Because society labels people with SCD as sicklers-lanky sickly people who have no strength, parents hate such a stigma to be attached to their children” (HW).

Another concept of key importance here is that of the loss of identity or self (Charmaz, 1983), especially the sense of loss experienced by the mother upon the birth of a child with SCD. Parents were known to lose their identity to assume the new social identity of the ‘one with that sickly-lanky child’-courtesy stigma. Though Charmaz’s concept refers to that of the patient himself, the concept can be equally likened to the parent who economically, socially, psychologically and emotionally empathises with the child and gives ‘all’ in the care of the child.

Social commentators argue that mothers do most of the emotional work in mediating the discrimination of society against their children (Read, 2000). In this study, mothers reported giving up their means of livelihood (loss of economic self) to care for their SCD children. As one health worker put it:

“ 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.”

In the light of the social interpretations of the disease, it could be inferred that parents are very selective about whom to disclose or discuss the news of their child’s condition with. Selection of such confidantes bordered fundamentally on the value of the person as a source of support in times of crises. Respondents informed their best friends because they have been their closest confidantes. They informed their parents or in-laws for marital reasons or to ensure appropriate child care should they have to be care takers for one reason or the other. Their siblings (of same parents or cousins) may also be informed in

order that such siblings exempt them from other familial financial responsibilities in view of their having to save up to meet cost of care. They would also be informed because of regular association of their families with each other as they visit. The last but not the least are their work colleagues. Such co-workers would have the privilege of knowing only when they have been able to build a social bond with the parents that qualifies them as ‘family’.

By virtue of these underlying categories of who to share the information with, it is possible for some parents to suffer psychological and social isolation should they live in environments where nobody they perceive as family lives. The following section discusses yet another of the discourses on SCD emerging from the findings of the study, that is SCD as the cause of recurrent death.

SCD: The cause of recurrent death

Nzewi (2001) in her study of recurrent reincarnation among the *Igbos* of Nigeria recounts the widely accepted belief among that ethnic group that everybody was reincarnated (*ogbanje*). She further went on to describe *malevolent ogbanje*; a revenge-driven concept that underlies chronic illness and repeated cycles of birth, death and reincarnation. According to Nzewi, this concept was attributed to SCD in her study and showed a family history of child death and death-related names as a means towards breaking this repeated cycle.

This evidence has strong parallels in this study where respondents reported such beliefs of recurrent death (*awo m'awuo* in Twi) and reincarnation about SCD. They explained

that there are lay beliefs surrounding the birth of SCD children as bordering on repeated cycles of birth, death and rebirth. As such, parents and families give what are termed as dirty or death-related names to children born after recurrent death experiences in a bid to culturally resist the disease. It is believed that such resistance takes place by the spirit behind the recurrent death rejecting a body with a bad or detestable name. Such names include '*sumina*' meaning garbage; '*sei ntoma*' meaning you waste cloth; '*begyina*' meaning stay live or don't die; '*te na baabi*' meaning stay somewhere; '*yadee eye ya*' meaning suffering from a chronic illness is a painful experience; '*ababio*' meaning you have come again.

Some also gave the names of fetishes (inanimate natural or cultural object believed to have magical power, either from a will of its own or from a god that has transformed the object into an instrument of its desires) to such children names such as '*Bosompra*', meaning the god of River '*Pra*' are given to thank them for giving them a living child (Sarpong, 1974). The concept of naming a child after someone in appreciation for what they may have done or for their achievement in life is customary in Ghana and underlies most of the naming ceremonies conducted on the birth of child. People would name their children after the parents, grandparents, childless or achieving siblings, friends, bosses, presidents and chiefs etc.

In an interview with F4, a forty-eight year old father of six children, three with SCD (one deceased), he said:

“Looking at them physically, she and the boy who died look so much alike. If you believe in reincarnation, I would have said she is the reincarnated version of the boy. Only that she is not that brilliant” (F4).

Implicit in this statement is F4’s conviction that the son who died might have been reincarnated with a different gender and academic capability. It could be inferred then that supposing F4 had experienced serial death among his children, he would have attributed it to SCD re-incarnation rather than the probability that being a trait couple they had a twenty-five percent chance that each pregnancy will turn out to be that of an SCD child (Ohene-Frempong and Dennis-Antwi, 1995). Interestingly, the fathers interviewed noted that gradually the belief of SCD re-incarnation is changing among those who have had the opportunity to receive factual medical knowledge on the disease and its inheritance. This suggests that public education on the inheritance of SCD has great implications for helping individual, family and society as a whole in redefining their concept of SCD as a genetic disease rather than a malevolent ‘*ogbanje*’ or ‘*awo m’awuo*’ (recurrent death).

Managing SCD as a metaphysical construct

So far in this chapter, the researcher has presented the social concept of health, illness and chronicity as well as the variety of categories associated with SCD in the Ghanaian society as a result of long standing experiences of families and communities with SCD, and for which they have constructed and reconstructed meanings and explanations (Burr, 2003) to the repeating manifestations, death and rebirth of SCD children, and for which no tangible cause could be ascribed outside of metaphysical causes. Subsequently, the

researcher sought to know from respondents how society then addressed the problem of metaphysical causes for SCD.

Respondents recounted that should a couple and family believe that the cause of the child's illness is metaphysical, then the afflicted couple do not passively accept the social diagnosis of the child but seek a metaphysical solution. For instance, for a belief in reincarnated children sent metaphysically to bring pain, child loss and despair, couples visit shrines, prayer camps and spiritualists (Ebin, 1982; Cornwall, 2001) to ascertain the reasons behind the afflictions and the solutions to prevent recurrence. By so doing, the newborn child is given an identification mark (*donkor* in Twi) on key parts of the body (face, shoulders, wrist, ankles or feet) so that when it happens to die and is reborn those marks would be evident thereby proving the reincarnation.

Identification marks is a complex sociological concept that could serve as a topic for comprehensive study in West Africa. Its significance ranges from branding during wars or slave trade, protection against evil spirits, a sign of beauty as in the Yoruba of Nigeria, sign of physical strength as in some northern communities in Ghana to a sign of ethnic identity. For each of these reasons, the marks are made in peculiar patterns on the face or on a selected part of the body.

In SCD, scarifications are commonly executed in sets of three or four tiny strokes on the shoulders, wrists and ankles, waists, chest or any part of the body affected by painful

crisis. Apart from that, there is also the belief that marking the child causes it to live and not die as the spirit behind the recurrent death becomes arrested. So if the child dies, it cannot come back, as it will be recognised immediately with the identification mark (Sarpong, 1974; Nzewi, 2001).

“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]

“What I know is that when a woman experiences recurrent death among children, often people do not associate it with SCD as such. What I have heard is that recurrent death is believed to be attributable to a child who is born, dies and is reborn. So that same child keeps being reborn. When death among children occurs successively for such a mother, a subsequent baby is given a mark of identification. This is done by inflicting marks on the face of the child or any other part with the belief that if it dies, the next baby to be born (reincarnated child) who is believed to be a rebirth of the previous child would show those marks. Most often, when the child is given such scarifications they do not die and are referred to as “Donkor” meaning one with facial scarifications” [HW]

Respondents noted that sometimes families could go the extent of breaking the bone of the dead child e.g. the leg just to ensure that the child does not return. If it should return, then it will show that defect.

The extreme of steps taken to resist recurrent death, as reported by the health workers, is the dissolution of marriage on the pretext that the couple is incompatible blood-wise. Another action reported is the putting of rings and amulets collected from fetishes around the limbs and necks of the affected child with the belief that it will drive away the metaphysical powers.

[.....] *“They either seek for spiritual protection from a source mostly fetish or the marriage is dissolved because they believe the couple may be incompatible. [...] They put rings and amulets collected from fetishes around the limbs and neck of the affected child with the belief that it will drive away witchcraft”.* [HW]

It was also established that in order to remove the bad omen of recurrent death, the pregnant woman may be given some special preparation to add to her water to bathe. This same preparation is used to bath the baby until the child is about a year or so when the spiritualist and family are convinced that the child will live.

“Also when the woman is pregnant, she may be given some special concoction to add to her water to bath. When the baby was born, that same concoction is used to bath the baby until the child is about a year or so when it is apparent that the child will live. I am saying all these because I had a sister who lost two children successively and she was taken through all these rituals and the third one lived”. [HW]

For SCD children with chronic splenomegaly, a medical condition in which the spleen is chronically enlarged as a result of excessive destruction of the sickle cells (Hioe and Sills, 2003), respondents noted that it was metaphysically perceived as a witchcraft pot sitting in the belly of the affected patient. Sickle cell patients with leg ulcers, a chronic condition common with haematological diseases (Dowsett, 2005) are also perceived as witches and wizards who use their legs as chopping boards for the human meat they spiritually acquire.

As a result, spiritualists are sought to exorcise the pot and the wizardry spirit from these patients, as the following narratives confirm:

“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. Some visit spiritualists and traditional medicine men for rituals to remove the ‘pot in belly’ or to heal the leg ulcer by exorcising the witchcraft or wizardry. In the course of the rituals, scarifications are made on parts of the victim’s body. But now education has thought us

that all these signs they consider as spiritually caused are as a result of the complications of the disease”. [F5]

These findings raise considerable implications for human rights protection as well as psychological implications for a patient who already is suffering from social stigma and alienation as a result of a condition (s)he has inherited through no personal fault. These narratives suggest that the social milieu in which the SCD patient lives in Ghana in itself presents difficult challenges. Faced with such challenges, it is only the strong willed patient and family who will be able to mitigate the impact of such discrimination and thereby improve on the quality of life of the patient. It seemed also that patients who had access to better health care in the towns and cities had a chance of surviving the negative discourses surrounding SCD because of the opportunity for access to clinical care and education programmes that provided factual information about the disease.

“But now education has thought us that all these signs they consider as spiritually caused are as a result of the complications of the disease”. [F5]

Conclusions

A reflection on Chapter Five as a whole provides the reader with an in-depth account of respondents’ perceptions of the social meanings of health, illness and SCD as a chronic, socially unwelcome disease. Findings pointed to five categories of the concept of health namely health as: sense of wellbeing; ability to exhibit physical strength, resource for economic endeavour; product of healthy lifestyle and clean environment and three categories of the illness state including illness as a source of: distraction; erosion of confidence and deviance.

The meanings fathers ascribed to health and illness offer lessons for understanding the concepts within the Ghanaian socio-cultural context. They represent a body of knowledge with a potential for providing teachers of HCW especially nurses, doctors, pharmacists and even social workers in the health delivery system with the needed foundation on the social context of health and illness and to promote the application of these concepts in the day to day interactions with patients at all levels of care. They also offer ideas for developing learning tools for helping parents of SCD children explore their feelings about SCD within its steady and illness states.

The accounts of fathers on chronic disease and SCD indicated that they had been exposed to competing theories of SCD in popular discourse. The implications of these findings to SCD programming is in the importance of creating a conducive learning environment within which fathers can explore the competing theories of SCD causality in a bid to arrive at a meaning that helps them to take advantage of the best of out of these theories.

Fathers' knowledge about SCD was identified to be a mixture of factual medical knowledge blended with experience, myths and lay conceptions. The existing knowledge as well as home remedies on SCD that fathers have prior to their introduction to the medical model of SCD is important in understanding the basis for some of the complications that patients may present at SCC for treatment. They also provide lay knowledge that is relevant to the training of HCWs in haemoglobinopathies in both Ghana specifically and perhaps more widely in Africa as a whole.

SCD is a disease stigmatised in society to such an extent that several discourses have been constructed within the context of the day-to-day experiences with the disease. These perceptions, however, are not likely to entirely override the variety of names and longstanding lay categories ascribed to SCD in influencing the social meanings fathers ultimately attach to the disease. The lay categories include SCD as a bought disease, a financial drain, the cause of early death, a symbol of recurrent death, a social stigma and as a metaphysical construct. Families have sought to explain the cause of the disease by attributing it to metaphysical causes, and to this extent may also be persuaded to seek metaphysical remedies to the problem. These reports suggest that the social milieu in which the SCD patient lives in Ghana does, in itself, present difficult challenges. Generally, findings in relation to lay discourses raise considerable implications for human rights protection as well as psychological implications for a patient who already is suffering from social stigma and alienation as a result of a condition (s)he has inherited..

Public education on SCD in Ghana seemed to be a recent phenomenon which has helped families who have had access to it to better understand the disease and take advantage of the clinical care services available in the cities to improve on the quality of life of affected persons. There are several implications that these findings raise for Ghana to consider in providing equitable client-centred services in SCD management that takes into account the socio-cultural aspects of SCD as well as improved accessibility to such specialised services.

In the ensuing chapter, the researcher moves on to describe the social impact of SCD on fathers and the coping strategies they harness to deal with their situations, their hopes and aspirations for the future of their children with SCD, and what they perceive the health care system in Ghana could be doing to improve on the quality of life of their child as a sickle cell patient.

CHAPTER SIX:

THE SOCIAL IMPACT OF SCD ON FATHERS

Chapter Five explored the social meanings respondents attach to health, illness and SCD as a chronic, socially and culturally unwelcome disease in Ghana. Findings suggested that SCD by its nature is a disease stigmatised in the Ghanaian society to such an extent that several discourses have been constructed within the context of everyday encounters with the disease. Moreover, public education on SCD in Ghana seems to be a recent phenomenon which has helped families who have had access to it to better understand the disease and take advantage of the clinical care services available in the cities to improve on the quality of life of affected persons.

Closely related to the social meanings respondents attach to these phenomena of health, illness and SCD are the social effects of SCD on parents. These meanings of SCD impact both on their life as parents and on the approaches they adopt to counteract these effects or integrate them into their lives as a newly constructed form of normalcy. This final chapter on the analysis of the data gathered from this study gives an account of the impact of such effects on fathers and the coping strategies they employ to deal with their situation. Findings of the assessment indicate an evolving process of social behaviour comprising such themes as: i) The social meaning of fathering a child with SCD ii) Extending care to SCD children iii) Challenges associated with paternal care iv) Beyond the horizon of SCD and family relationship v) Coping systems in fathering a child with SCD and vi) Recommendations for paternal involvement. Also described as part of each

theme are the implications of the findings for health care and social support provision for affected families in Ghana.

'I was sad', 'We were devastated', 'SCD so what': The Social Meanings of Fathering a Child with SCD

Generally, living as a parent of a child with SCD involves the active engagement of the social, cultural and material resources at his disposal to address the challenges of the illness (Beresford, 1996). Available literature on social aspects to SCD suggests that parents are often confronted with physical, emotional and financial difficulties in their day-to-day experiences with SCD (Anionwu and Atkin, 2001). Accordingly, the researcher in this study sought to find out the extent to which fathers were affected by the birth of an SCD child. The reactions of the fathers are discussed below:

Reactions to Diagnosis

According to the thirty-one fathers, there were two main ways through which their children were diagnosed with SCD. About a third (11) of the fathers had their children diagnosed through newborn screening whilst the rest (20) had the diagnosis determined after series of bouts of childhood illness (recurrent fever) or poor growth. As described in the second chapter of this thesis, newborn screening for SCD in Ghana is a programme that ensures that all children born in Kumasi, the second largest city in Ghana are screened at birth for SCD. Children who are confirmed to have the disease are then enrolled into a continuous medical and educational care programme to improve on the quality of life of the child.

Upon diagnosis, fathers exhibited two main reactions: that of nonchalance, or alternatively that of extreme worry or shock. The reaction characterized as nonchalance was an outcome of two different processes. On the one hand some fathers were familiar with SCD in the sense that they had heard of the disease and seen it in their family. On the other hand, some were nonchalant precisely because of a lack of technical knowledge about SCD. Both familiarity and lack of familiarity, in their different ways, produced the reaction the researcher is terming nonchalance. Of the few (6) who were nonchalant, some explained their reactions as follows. F8 said:

“I was not all that worried when she (wife) came to tell me about it. I had heard of newborn screening on TV. Besides, SCD was no new thing in my family as there were about 3 or so people I knew in the family to have the disease”.

F10 also noted:

“On the day I was informed about the diagnosis, honestly, I did not know much about the disease. So I did not understand what it meant. It was like ‘If she has SCD so what’ ”.

It was apparent that the reactions of fathers did not imply lack of concern for their children but rather that stemming from a past experience with the disease or minimal insight about the pathology of the disease. They used expressions like ‘*It’s no new thing to me*’, ‘*When I heard the news my mind went to my first child who died*’, or ‘*did not know much*’ to explain their positions. Their attitude could be likened to their perception of SCD as a disease whose degree of impairment or disability, as defined by the prevailing social construction of normality and abnormality, is more acceptable in comparison to disabilities such as mental conditions. This is because mental conditions are socially perceived as more stigmatising (Katbamna et al, 2000) and are accompanied by especially negative societal attitudes. Although SCD is a stigmatising disease, as

reported in Chapter Five, it seemed that the level of stigma felt by the six respondents, and in turn the nature of their reactions, was highly dependent on their previous exposure to or experience with the disease.

On the contrary, the remaining twenty-five fathers expressed negative reactions to the diagnosis of SCD in their children. According to them, they greeted the diagnosis of SCD in their children with a lot of uneasiness, sadness, discouragement, apprehension, depression or withdrawal and a presumption that their children would not live long. To them a death sentence had been passed on their children and there was nothing to look forward to in the future of such children except continual illness, financial and time loss as well as emotional stress. The following are some excerpts from their discourses to reflect their emotions when they heard the news.

“F3: We got to know when the child was about 2 months old. Hmm! I was sad because it occurred to me that I could lose the child at any time. I was sad that I child I love so much should have this disease.

Res: You say you did know much about the disease so why were you sad when you received the news?

F3: Ok! I had heard people say that such people did not live long. Actually when you see the child ill, it is very sad. You know that things are not just going well with him?

Res: What do you mean by things not going well?

F3: You can see the child is weak. ‘Like an old person almost at point of death’”.

In comparing the reaction of F3 to that of F10 quoted above, it is evident that though F3 did not know much about the disease just like F10, he reacted differently because of the exposure he has had with folk theories and popular discourses on SCD. He reported that he had heard discouraging discourses on the disease that portray it in a negative light thereby justifying his gloomy outlook to the course of SCD in his child. He again affirms

his conviction of the truth of the folk theories on SCD by stressing that SCD children are weak and look *'like old people at the point of death'*. Implicit in this statement is the feeling that children who do not fit into the social perception of normality are generally unacceptable.

The statement therefore could be a powerful tool capable of long existence in the collective memory of society, resulting in a revolving and perpetual negative attitude to SCD in Ghana if no efforts are made to address them.

The notion of nonchalance due to lack of knowledge about SCD underlying reactions to diagnosis was further reflected in the report of another father (F4), who noted that, with his first child, a diagnosis of SCD meant nothing to him. However, by the time he had the second child, he had gathered enough experience with SCD to make him react with deep worry. He noted:

"For our first child we had no worry because we did not understand the disease. But for the 2nd child it was not easy. My wife was devastated and cried a lot because we had no regular income and if we reflected on how much money we had spent seeking clinical care for our first child, we knew we were in for a lot of trouble". [F4]

Similar sentiments were described in yet other reports as a result of folklore theories about the disease, past experiences and comments from health care providers who were generally perceived as custodians of credible medical knowledge.

"Honestly we were devastated. We did not know much about the disease but the information we got from the Lab and hospital contributed to these feelings. We were told she had SCD and that she will not live long". [F14]

"Yes I was disturbed because it reminded me of my nephew who died of the disease. I was really disturbed. I said to myself "so am I going to care for this child only for her to die?" [F16]".

"When I found out he had SCD, I felt for the child and my heart went out to him".[F29]

Much of the evidence in these discourses, both for those who showed nonchalance and those who exhibited negative reactions to the diagnosis of SCD, strongly suggest a direct relationship between the level of reaction to diagnosis and individuals' perceived knowledge about the disease, previous practical experience with the disease or what has been said by laypeople, and even in some instances, qualified health workers.

Unfortunately, it could be that the folklore upon which the fathers base their reactions is derived from only one side of the spectrum of SCD experience (see Chapter Five). Thus those people who have had bitter experiences with the disease provide further morality tales that reinforce prevailing folklore, whilst those with uneventful experiences perceive SCD in a different light that do not make for good folklore. For instance, in the statement of F8 quoted above, he commented that though he was familiar with SCD as affecting about three family members, he was unperturbed because he had previous knowledge about the disease and probably the family members who had the disease were living positively so there was no need to be overly distressed about the diagnosis.

Of particular relevance to SCD is the financial implication of care much of which has already been outlined in as a lay discourse in Chapter Five. Notes by respondents on their reactions to the diagnosis of SCD underpinned the strong fear of the financial repercussions of fathering a child with SCD. Comments like '*illness means debt*' and '*you must be ever prepared financially to meet his medical cost*' signify the huge burden that SCD places on parenting. In at least three cases, this fear was so strong as to take away the joy of parenthood and replace it with anxiety and depression. F6 and F15 said:

“Having such a SCD child is a big responsibility for the father. You must be ever prepared financially to meet his medical cost”. [F6]

”But when I was informed, I was really shaken. Who likes to hear of disease? Illness means debt”. [F15]

The statement by F4 vividly sums up the notion of the financial burden of SCD on fathers.

“My wife was devastated and cried a lot because we had no regular income and when we reflected on how much money we had spent seeking clinical care for our first child, we knew we were in for a lot of trouble. Surprisingly, days that you don’t have money, that is when the child gets ill. Sometimes you go through hell to raise a loan to take the child to the hospital. So when I had the second one honestly, I was depressed for that first week of knowing his status”.

The Process of Resolution

In the midst of all the feelings of devastation, depression, nonchalance and loss of hope was the critical need for the fathers to decide with the mothers of their newly diagnosed babies or children what they were going to do. When asked what decisions they took after the diagnosis and their reasons for arriving at those decisions, the responses given by the fathers showed a pattern of individualised process of grieving characterised by blaming, confirming, justifying and accepting before arriving at a decision, implying a process of resolution at play. Five fathers directly or indirectly blamed their wives for the crisis by capitalising on the clinical information that their wives were to report at the SCC for confirmatory testing of their babies. According to the specialist health workers interviewed in the course of the study, confirmatory testing of the newborn’s genotype was supposed to be carried out on both the father and the mother but it was common occurrence for the fathers not to turn up, thereby resulting in the testing being carried out only for the mothers. Most of such fathers therefore never test their genotypes to know their trait status thereby perpetuating the myth that mothers are to be blamed for genetic

diseases. F20, a father of six with one SCD child noted concerning the mother of the SCD child (whom he had divorced):

“When I learnt what SCD was about and its effects I realised that I had a big problem to contend with. I had not experienced any of such things in my previous children so I was very upset with the mother of my child. Apparently she knew she had the disease (SS) but hid it from me when we were together. But the knowledge we gained when we visited the clinic means there can be hope”.

F11, a thirty-seven year old father of one also said:

“My wife told me the clinic had invited her to come so they could recheck because they were not sure what they found”.

To them, health workers were requesting their wives to be tested because they were the likely cause of the disease. This implies that the newborn screening programme needs to find ways in which to communicate to the father the importance of the diagnosis of SCD, and the fact that SCD is genetic and therefore implicates both the father and the mother.

The fathers made comments implying their exoneration whilst encouraging the women to go for the testing to confirm disease. It was a typical scenario of locating the cause of their children’s disability in the genetic disposition of their wives or partners. Another way of blaming their wives was to express anger for knowing that their partners were sickle cell traits or patients. This is despite the fact that the fathers may not have checked their own sickle cell status. This implies that an additional advantage of involving more of the fathers earlier in the process of contact with the health services could be to reduce the availability to the fathers of their blaming strategy because they themselves will have been tested for sickle cell trait at the first visit to the SCD clinic.

The researcher notes that in the typical case of F20, confirmatory testing proved that the mother was SS thereby justifying the father’s anger at the woman. However, it is possible

that the woman never knew she had SCD. Apparently, the woman grew up in the village where there was minimal medical knowledge about the disease. She was reported to have suffered bouts of bodily pain ‘*ahotutuo*’ (painful crisis) in her childhood and was treated locally. Over time as she got older, the frequency of ill-health decreased considerably such that even in her relationship with the F20 there was no major crisis to warrant a revisit to her childhood life of painful crisis. Hence the expression of anger by F20 that he had been deceived.

Justification of paternal feelings to the diagnosis of SCD was similar among most of the fathers in the study except two. Whilst most of the fathers indicated that there was nothing they could do in the circumstance other than to accept the child as it is, the two fathers felt that it was best not to contemplate marriage because there was no point in continuing to produce children with SCD. F13 stated:

“I honestly thought it would be wise to end our marriage then. Because for us to stay in marriage and continue producing such children would be no benefit to us”.

F3 also said:

“Presently we are not married. Since the birth of this child, I have been contemplating putting a stop to this relationship because we are both young and it is possible for us to meet future partners who can give us non-SCD children. So we (myself and the lady) came to see Dr X. But in the course of the discussion, the lady did not seem to understand the importance of us breaking. We therefore agreed that may be it is not yet time for us to deliberate on breaking the relationship until the child grows to school going age then we can separate. I have even proposed that at that time, I am prepared to take the child so the mother would be free to get on with her life”.

Further on in his discourse F13 indicated a change of mind as part of his process to resolution resulting from a reflection on his Christian belief and principles.

“In the end we decided to get on with our marriage. What facilitated this decision? Our bible belief that marriage is till death we part was instrumental in that decision”.

F3, on the contrary, was set in his mind not to marry because he had the opportunity to withdraw from the relationship due to the fact that the child was born in the course of courtship rather than traditionally accepted marriage. This position signifies that the birth of a SCD child out of marriage creates an unstable milieu within which the child must grow. Such a situation raises serious implications for improving the quality of life of the child as there is a tendency for parental disagreements to influence decision-making in childcare.

Of the majority (29) of fathers who felt they had no option than resign to what fate had brought them, they resolved their decision to accept the child by confirming their Christian faith. With God's strength and provision they would do their best for their children. They made statements such as:

"We made up our mind to accept the child as she is. That is what God has given us and we must accept her and take good care of her. We pledged to do our best for the child. Besides the education we received from you people at the clinic served to encourage us to care for the child and to know that the child could live long to a ripe old age". [F8]

"We gave it up to God and committed ourselves to hospital care because we believe that it is God who gives wisdom to the doctors to care for our children. I don't have any other means of addressing the condition so our belief is that all the education we receive will be useful in caring for our child" [F14].

"When such things happen, what can you do apart from commit it to the hands of God? Some people with the disease have lived to 60 years some are 40 so you also pray that rumours such as that they die by 15 years will not be your lot". [F21]

"But I was encouraged by the words of Paul the Apostle. He said, "I can do all things through Christ who strengthens me". So I put away all sorrow and put my trust in the Lord.So as for SCD, Hmm! Madam, I know what it has done to me. It does not allow me to progress". [F4]

Another factor that facilitated their positive decision-making was the continual education they received at the SCC and the support group meetings. The fathers reported that

parental education on SCD had played an immense role in helping them develop positive attitudes to the care of their SCD children.

In their accounts, fathers reiterated their desire and hope to do the best that they could in their circumstances and within the limits of mainstream services available and to leave the rest to God. That was the only option they felt they had. They also reported feeling encouraged because they had the opportunity to see other families equally affected by the disease and to become aware that it was possible for their children to live to forty to sixty years rather than die. They were optimistic that the hospital care and continual education was the promising pathway to better quality of care for their children because the dominant cultural and social values surrounding SCD were more pessimistic, gloomy and distracted from positive image building of the SCD patient.

Notwithstanding this positive outlook, there was a father who expressed difficulty in effectively achieving his desire to do his best for his child because of lack of cooperation from the child's mother in her care. F23 noted:

“Well what is important is the routine check up and the clinic when the child is sick. I also support them in attending the education sessions to learn about the disease. I would have wished to go once a while but the time is my problem. I am always on the road. I feel that in such circumstances she the mother should have been the strong pillar for the child to lean on but she is not doing that. Now the child is ill. I will ask her elder sister to go with her to the hospital”

This statement suggests a degree of paternal dependence on the mothers of the SCD children for their optimal care. It is also apparent that the type of work fathers do, and a paternal conviction that women ‘should’ be interested in childcare because it is their traditional responsibility to do so, influences the degree of paternal dependence on the

mother. There is a notion of 'passing on' in this context. In Chapter Four a description of the context of traditional division of labour in Ghana was outlined and the evidence indicated that a majority of the fathers felt their moral responsibility was to provide leadership and security to the family by confirming, checking, providing needs and ensuring that the family was doing well, whilst the woman had a greater duty of more direct care. This expectation surely underlies F23's disappointment in the role of the child's mother.

This finding underscores the need for creating cooperation as part of genetic counselling between both parents of a SCD child towards optimal care in health promotion and sustenance. In pursuit of such optimal care, it is important that the traditional division of labour is taken into account and its strengths harnessed in a way that ensures parental commitment in whatever circumstances they find themselves: whether the caring responsibility is complicated by paid work, separation in marriage or divorce.

Another factor of outmost importance in the social impact of SCD on fathers is the diversity of strategies employed by fathers to extend care to their SCD children and the challenges associated with such care. The following section describes findings among the fathers interviewed.

'Being there', 'Preventing bad play', and 'Dealing with baffling questions': Extending Care to an SCD Child

Evidence from sociological literature indicates that caring for a disabled child or a child with a chronic illness is a daunting task and most parents (carers) have adopted socially constructed and partially medically appropriate strategies to deal with it. Much of the literature focus on the impact of chronic illness on mothers as carers whilst the exact roles that fathers play in the care of SCD children or children with chronic conditions and the effects on them as fathers remain largely undocumented (Midence and Elander, 1994). In this study, the researcher sought, as one of her main concerns, to determine the exact care that fathers give to their children with SCD and the impact of such care on their lives. In the following section, she gives an account of findings from the interviews and what their implications are for social policy.

Extending care during illness's steady state

Typically, the care that fathers extend to their SCD children when the child is not ill is not significantly different from what they would do for the rest of the children in the family. In Chapter Four, the fathers reported that they perceived their role in family division of labour as checking, confirming, ensuring, advising, and instilling moral discipline and an appropriate respect for God. Similarly, fathers noted that extending care to their SCD children in steady state meant supervising school work, reading, chatting with the child and listening to music of their choice, playing indoor games, watching TV,

assigning them to household chores within the limits of their (SCD child) capabilities and setting controls towards protection from ill-health.

“On such days, after the morning activities, if there is nothing else to be done, he has so many friends he goes out to play with or he joins us to watch any interesting programme on TV. I don’t single him out for anything special. I treat all the children equally.” [F10]

Though caring for the SCD child in a steady state meant carrying out similar activities as they would have done for the general family, their accounts also referred to certain specific tasks they performed to ensure that their SCD children stayed safe and healthy as much as possible. This included preventing them from activities that were perceived as triggers to illness. Such triggers i.e. boisterous playing, playing outdoors in cold weather without wearing protective clothing were considered as ‘*bad play*’ because they often resulted in a painful crisis and therefore a disruption in the usual routine of the day.

“In the house, I try to control his playing habits” [F17]

“I try to keep them with me as much as possible to prevent their getting involved in any bad play. I also sometimes tell them folk stories or share the words of the bible with them so they will live uprightly. I am a Sunday school teacher.” [F25]

Other tasks were checking that they had taken their medication, and that there was a sufficient stock of folic acid and multivitamins available. They also provided them with anything that will make the children feel comfortable, such as applying hot compresses to their mildly aching joints and chatting with them.

“Basically I ensure that she takes her medications regularly”. [F2]

“I see to it that his medications are always available especially folic acid and daraprim (a malaria prophylactic)”. [F21]

“If it is a cold day I keep her indoors a lot. I ensure that she is well clothed. I apply hot compresses to her limbs and then we listen to music”. [F15]

In chatting with these children, those fathers who have had regular access to SCD education (10) lost no opportunity in sharing and comparing notes on the medical knowledge of SCD in order to assess the children's compliance to the medical regimens handed from the clinic. In discussing SCD, a father (F17) reported a surprising question his son asked him one day. The question served to convince him that creating the congenial atmosphere for talking about SCD helps to clarify any negative notions that the children might have formed about themselves, and encourages them in positive living.

In his discourse he said:

"[.....] I ensure he gets involved in household work but to his limit. I educate him about the disease too. There are times when he asks questions too about his condition. I remember one time he asked me a question that baffled me. He said "Dad I have been taking drugs daily all this while so when am I going to stop it because it seems I am the only one amongst my siblings who is always taking drugs". That is why I educate him to know about his condition so he does not brood over it too much".

Daily intake of drugs by SCD patients, though protective and perceived as a very important parental responsibility, commonly becomes repulsive and a drudge to patients as, besides their physical features, this activity is what distinguishes them from their peers as they grow up. It is not uncommon for parents to complain about the difficulties they go through to get their children to take medications as they grow up. It is possible that early interactions with patients by parents and health care professionals on their condition, and educating them on how to positively live with the disease, could significantly influence patients to be more cooperative with their care when they grow up and also equip them with strategies for coping with habits that set them apart from their peers.

Another way in which fathers said they extended care to their SCD children in steady state was ‘being there’ for them. They reported holding hands, staying indoors, going out on rides, strolling, sleeping together or lounging with them. Two fathers indicated that above all they ensured that their children got involved with household chores as a way of contributing to family life.

“I ensure He gets involved in household work but to his limit”. [F17]

“On holidays, as a family we all go to the family farm to grow some food crops and he goes with us and participates to the best of his ability. He does not like to be isolated or put away. He will insist to take part. He is troublesome I tell you. So we give him his due to participate”. [F30]

Involvement of SCD children in household activities is perceived here to be an important aspect of preparation towards adult life. Teaching SCD children how to perform common household tasks serve to encourage them and to make them feel part of the family. Such actions are reported in the literature to improve sibling relationships and to remove a feeling of preferential treatment for SCD children. It is possible that programmes aimed at teaching parents how to prepare their SCD children towards independent adult life could benefit from such lessons to develop strategies that take individual patient’s capabilities into consideration.

Unfortunately not all the children of the fathers interviewed had the opportunity of having their fathers ‘being there’ for them. Eight fathers reported that since they did not live with the children, they were not able to extend care on daily basis to them. Rather, they gave care by proxy either through the mother of the child or relative with whom the child was living with. On the few occasions when they were able to meet with the children they interacted with them as best as possible. Such fathers were separated from

their children for reasons such as divorce, marital separation or convenience (child receiving better education or access to health or parental care). Only two (2) marital separations were attributed to SCD itself.

“Because I do not live with her on daily basis, whenever she came to me for the day, I went everywhere with her including even visiting my friends. Presently she does not come as I indicated because of the problems I have with her mother”. [F16]

“The child is more attached to the mother because I am most often at work and living with my new wife now though we live in the same town. I close from work at 5pm. I get home at dark so I don’t get to see the child daily”. [F20]

The fathers did not clearly state the emotional effect that living separately from their children had on them but it was apparent from the discussion that they were not very happy with the situation and felt distressed. They wished otherwise. Five fathers had allowed the mothers to keep the children because they felt it was the best thing to do in their current circumstance (F16, F20, F23, F31 had each remarried) or the child was too young to be separated from the mother (F3). They had a feeling that if they were present, the quality of care that the mothers gave to the children could be better because they would be able to effectively play their expected traditional role of checking, confirming, ensuring and instilling appropriate moral discipline. F23 was clearly upset, and he felt powerless to change the situation.

“I have a desire to have my daughter with me so I can supervise her eating but the mother does not allow that. This child wakes up at 5am to prepare for school when the mother is still asleep. There are times the child takes no food to school and she has to rely on her half-sister to share her lunch with her. I live for these children. If not why would I strive so hard? There is no reason why they should be in want. But the mother is not allowing me to take care of the children the way I would have wanted to”. [F23]

The feelings of distress and powerlessness apparent in some fathers who do not live with their SCD children could be contributory factors to, or the underlying reasons for, continual discord between parents who are separated in marriage but have children with

SCD. Although SCD in itself may not be the reason for discord and marital separation, it is, following a divorce or separation for other reasons, a subject that becomes the site of potential disagreements between the parents.

The researcher further outlines the extension of care by fathers during times of illness and discusses how such care compares with that in the steady state.

Extending care during illness state

In the accounts of the fathers, extension of care began with noticing a change in the usual mood of the child. When the couple were convinced that the child was truly ill, they would apply first level treatment based on their lay expert knowledge or advice received from others who could be friends, relatives or health care specialists from the SCC. First level treatment ranged from the administration of routine drugs such as folic acid, tylenol, multivitamins to anti-malarials, energy-boosting drinks (lucozade) and cough syrups.

“When she is ill, I am able to tell because in her normal state she is boisterous, up and about. When she is not feeling well, she goes quiet. So all I do is to take her to the hospital. I have a cousin I go to see who would advise me on what to do. He may say I should give an anti-malarial called Halfan. He would also request for a lab test to confirm malaria. On my due appointment to the SCC, I would then explain to them about the child having been ill, what was done and the medication given. I always try to update them on what is happening with the child.”[F8]

Depending on the reaction of their wives, the state of the child and time of day, they would get the children to the hospital. The waiting time between noticing illness and going to the hospital ranged from immediately upon recognition of illness to three days after recognition. Most often, taking immediate action was influenced by knowledge

gained from the SCC or support group meetings directing them to report to the nearest health facility immediately they noticed fever. The following statements confirm the assertions.

“When ill, we do our best to minimise the suffering depending on how serious it is and based on the knowledge we have acquired through the Association. If symptoms are not relieved over time we send him to the hospital” [F4]

Usually the mother takes him to the hospital. I have accompanied her I think on 2 occasions. I remember the last time, the child had fever in the night and I felt we could observe him overnight and go to the hospital on the next morning but my wife insisted that the fever was getting worse so together we took the child to the hospital. [F11]

“When the child is sick, he has his regular medication such as folic acid which I give him. Then if he is coughing, I get a cough syrup from the drug store which he takes for about 2 days or Paracetamol if there is fever. If after 3 days he does not get well, we take him to the clinic. I drive myself to go if necessary”. [F12]

“We were informed in earlier education sessions that when the child is ill, we should send her to the nearest clinic and inform them that the child has SCD. But since we are near KATH, whenever she is sick, I let the mother send her over”. [F20]

In their reports, a majority (21) of the fathers stated that they would request that their wives send the child to the hospital, eight (8) that they would take the child themselves, whilst the remaining two indicated that their children had just been recently diagnosed and therefore did not have any experience with the illness state.

“When she is ill, it is often the mother who takes charge. Because of my work in the church, I often drop them at the hospital and pick them up later. There has been a time that she got sick and the mother had travelled so I took her to the hospital”. [F19]

Generally, fathers noted that their perceived roles during the illness state included overseeing the application of first line treatment, facilitating the process of hospital attendance by providing the financial and transport support needed, supervising administration of drugs prescribed, giving emotional support and expressing empathy. A few (3) fathers added that apart from the listed roles, they would pray as well to God to

seek for protection and good clinical management because God has the power to heal and to direct the medical team in proper management of the child. The following quotations further explain the point made.

“Ooh! When he is ill, my wife and I put in our extra attention to ensure that he gets the right medication. But no amount of money can buy the solutions. We leave it to the doctors to do their best -get the right medication at the right time. See the doctor at the right time in the right mood. That is why you need to be spiritually alert. Because things happen”. [F9]

“He is presently 7 years so when he is ill we pray asking God for his healing. I teach him how to pray so he could do it on his own more often”. [F13]

“In fact when the child is ill, I am also ill. I sit up all night praying”. [F15]

Implicit also in their statements is the fear that the medical team could make mistakes in the diagnosis and prescription of the appropriate treatment for the child. Therefore it was important for parents to seek spiritual grace from God so that the children would be sent at the right time to meet the right team and to be offered the right treatment.

On the issue of expressing empathy and giving emotional support, responses came in various forms and fathers used phrases such as *“my heart also aches with pain for her so when she is ill”*; *“In fact when the child is ill, I am also ill”*; *“I stay around him”*; *“I am not a happy man when she is ill”*, *“I stay with her”*; *“when she is sick, I feel sick too”* or *“I feel pity for her”*.

These expressions portray the emotions fathers go through as part of their experiences in parenting a child with SCD and, though they were not explicit in stating these emotions, it is arguable that feelings of fear, uncertainty, frustration, and pain underlay their statements. The reluctance to be explicit in stating their emotions could be due to traditional gender related modes of expressing pain common in most African cultures. There is a saying in the Akan language (language of over 40% of the population) of

Ghana that *'Barima nsu'* meaning *'A man does not cry'*. As part of enculturation, the male child is thought to be strong and avoid visible expression of emotions. In extreme cases when men have had to cry (e.g. death of mother, wife or child), they would often be consoled by the same statement to remind them that it is culturally unacceptable for them to cry in public. This cultural attribute may explain the concealment of emotions by the fathers interviewed in this study. However, it is worth mentioning that two fathers cried as they narrated their experiences with SCD and this may have been made relatively more possible because they were alone with the interviewer and were not therefore in a fully public arena.

To determine reasons why fathers would request that the mothers send the child to the hospital rather than themselves going, the researcher posed the question and fathers outlined interesting reasons for their line of action. Details of this have been discussed under *'Challenges associated with Paternal Care'*. Of the fathers (8) who reported accompanying the children (without the mother), they did so because they felt they were able to better handle the situation (more courageous, better able to communicate with health professionals or negotiate for better care) than their wives, or that their wives were unavailable for one reason or the other. F 4 noted:

"At the hospital, what I do is to get the medications prescribed for him. If he is admitted, I as the father stay with my own child and provide for all his needs until discharge. Most often I am the one who stay in hospital with my children because my wife has not got the courage to do so. She gets emotionally upset with a little problem. I try to keep her away from all the hospital experiences".

F5 also stated:

"When the child is ill, I find it my obligation to bring her to the hospital and I do just that. I have always brought her for medical care".

Should the child be admitted, they would stay with the child on admission and provide domestic care such as bathing or feeding as well. These actions by the fathers, which run counter to traditional roles and responsibilities, do signify the possibilities through which parents could re-negotiate the division of labour more generally in the care of their children with SCD. The next section reflects on the challenges that fathers go through to provide care to their children with SCD.

‘Breadwinners’ and ‘Hospital-Going as Women’s Work’: Challenges associated with Paternal Care

Thus far, this chapter has focused largely on the social meaning fathers attach to the diagnosis of SCD in their children and their manoeuvres in resolving the disruption in their procreative life. For many of these fathers, accepting the SCD child as a ‘gift from God’ gave them the moral responsibility and the conviction they needed to extend care to the child both in the steady and illness state and in a way directed by the traditional division of labour. Where it is very essential, these traditionally defined roles were re-negotiated and reconstructed to allow for optimal parental care. Provision of such paternal care was not without challenges, as described by the fathers. Challenges ranged from lack of time to accompany their children to hospital, financial problems coupled with marital conflicts, unpleasant encounters with health care professionals, to accepting the physical appearance of their children described in their own words as having knotted and contorted features and skinny appearance (*woayε ndwedwendwendwe*’ in *Twi*) as a result of delayed growth.

As part of ascertaining their perception of such challenges, the researcher firstly asked why most fathers would rather have the mothers bring the children in their illness state to hospital and to find out whether failure to do so was due to challenges associated with care or was as a result of traditional expectation. Findings showed that the fathers (20) primarily attributed their inability to accompany their children to lack of time. They reported that since they were employees, it was difficult to go off work and attend clinic or support group meetings. They also explained that most often their wives were self-employed and could therefore have personal control over their own time. Moreover, they, as men, had the moral obligation to look for the money needed to buy health care in a system where cost of care was relatively expensive and largely based on direct fee payments.

“On some occasions, it is an issue of time. As a man, you are responsible for meeting all the family needs especially when you are the sole breadwinner. As such you have to go and look for money whilst the woman also takes care of the house and the upkeep of the children. As she goes to the hospital, I look for money so that we can meet the hospital bill”. [F10]

When they were less busy some fathers made the effort to accompany their wives to the clinic to learn at first hand what goes on there. Roles were negotiated as much as possible on daily basis so where it was possible for the man to participate in the clinic activity he joined in. It was also apparent from their narratives that they felt the women had limits to their capabilities and therefore as they went to the clinic if any problem arose beyond the woman’s ability, they were expected to contact the father who is conceived of as the head of the household, a traditional responsibility accepted by the couple if they are still married, for the final decisions to be made. F15 noted:

Res: You indicated that today is your first day. What made you come today?

F15: I came because I was less busy today so I decided to come and listen and observe proceedings. Using myself as an example, I don't come mainly because my work occupies so much of my time. Besides I have to oversee the return of my children from school. As I sit here my mind is on these children because it is time for them to return from school. So we look at the task for the day and decide. I have made up my mind that if I have time I will come with her but if I am busy then I will give her money to come to hospital. If anything crops up beyond her limit, she can call me and I will come

Another reason given by the fathers for non-attendance at the hospital was their understanding that hospital attendance was the traditional role of women since they (women) have proven credibility by society for empathy and patience towards children. The fathers believed that such female attributes were God-given whilst the men were to ensure the women had what they needed (money) to go to the hospital. To support this argument F21 commented:

F21: [.....] Besides, hospital going is a woman's work.

Res: Why do you say that?

F21: Because it is women who have empathy for children. This is a God given part of women and not necessarily due to traditional roles. The man's responsibility is to ensure that the woman has what she needs to go to the hospital.

F27 added:

"You know, women are the key caretakers when children are ill".

Other reasons the fathers outlined why some men would not like to bring their children to the hospital included fear of stigma, belief that it is the woman who gave the disease to the child and therefore must bear the burden, typical male habits of non-involvement in household activities and psychological exhaustion from the financial burden of the disease.

On the other hand, one way through which the fathers demonstrated to themselves and to others that their love for their SCD children was exceptional, was to ‘break’ the usual conventions of the mother being the one who took the lead in caring

“I will comment on my attitude to my children. I’d say I love my children very very much. I do most of the things needed by my SCD child. I always take her to the hospital myself and most of the follow-up visits I bring her. Even my wife is not involved much. Most men do not have such love for their children thereby leading to such attitudes”. [F14]

An underlying factor in the willingness of some men to take up the responsibility of hospital care, rather than merely accompanying their wives, was their conviction that their wives would not be able to maximise the opportunity to seek optimal care for the sick child. They used phrases like *‘women are shy and would not ask the doctor the needed questions’*; *‘being a man I am able to quickly see the doctors and return to work quickly’*.

F12 recounted as follows:

“You know men when they hear something, they are able to keep it for a long time. It’s me who is able to tell when the child is getting sick because I am very observant of his actions more than the mother. So when I see that, I would ask the mother to take him to the hospital. I would then inform her to communicate any outcome to me”. [F21]

These commentaries by the fathers present the typical sexist attitude of the African man who has been acculturated to think that he is the custodian of wisdom and that even if a woman is educated to the highest level, she is still not wiser than the man. It is typical for the Akan society in Ghana to use a phrase like *‘If a woman buys a gun, she hangs it in a man’s room’* to signify the power and influence of a man. Therefore, much as the men felt the women could handle the children, they were convinced that they could do a better job when it came to interplay between the health care system and accessing care.

It is possible that they had to perform such roles because their wives were equally not available due to work or were not emotionally strong to stand up to the pressures of hospital care in times of crisis.

It can be inferred that though the fathers had good intentions and were effectively doing a good service to their children, their motives are inconsistent with modern day discourse on women's potential, and antagonistic to the achievements of single women who have made remarkable contributions to the advancement of society. It is important that programmes geared at increasing paternal involvement in health care for SCD patients aim at harnessing the concept of men as partners in the care of the children. This could be done by re-packaging the notion of traditional division of labour in a way that portrayed the couple as partners who supported each other in child care and who are amenable to constant negotiation on roles on the basis of social context rather than a stiff adherence to traditional roles. On the other hand, findings might also suggest the need for further research to see if the health professionals attend more to women's or to men's accounts of their children's illnesses and whether men do indeed receive more prompt attention than women in the health care setting.

The research findings also pointed to lack of finance as a major obstacle to accessing health care for the SCD patient. Most of the fathers, especially those who have had experiences with frequent bouts of ill health among their children with SCD, described painful experiences with trying to source money for health care. Some had to sell their personal effects to raise money or sought loans from small-scale loan schemes with high

interest in order that their children who were on admission at the hospital could receive medication. It was common for the fathers (29) to complain about the cost of drugs. They reported that most of the medications were very expensive for the average father to afford. The following are some excerpts:

[...] Surprisingly, days that you don't have money, that is when the child got ill. Sometimes you go through hell to raise a loan to take the child to the hospital. So when I had the 2nd one honestly, I was depressed for that 1st week of knowing his status. [...] There came to a time when the child got ill and we had no money. Even money to buy food was a problem. So what I did was to ask her to go to her parents in their village to look for financial help whilst I took the child to the hospital. I intended to see a friend there to help me with 10,000 cedis. [...] Apparently, when she got to the village, her mum was not there. She was trapped because she did not have even the little money for transport back to Kumasi to inform me of the situation. [...]. She went back, entered our bedroom and took the only good cloth she had, sold it cheaply and brought the money to the hospital. That is how we dealt with the situation. [F4]

[...] And we keep going to the hospital. Each medication prescribed is expensive. The last time it was 150,000 cedis. (£10 approx) Recently we had to buy another one at 200,000 cedis (£12.50) apart from other minor expenses [F28]

The experience I have had with the SCD shows that as a parent you will need to have a lot of time for such a child. It does not matter that the child wakes up feeling well. He could develop illness any point in time in the day. [...] The ultimate is to send him to the hospital [...] you get to the hospital only to be told your child needs to be transfused with blood. So it is a real problem. When you are going to the hospital you dare not go with little money. At least you need 400,000 cedis (£25) to treat the infections before the others. [F17]

[Note: Currency Equivalence, 2005: £1=16,000 Ghanaian cedis. Per capita income in Ghana is \$2,300 per annum which is an average of \$200 per month and an equivalent of 1,800,000 cedis. Most Ghanaians in private unskilled employment earn between 500,000 to 1,200,000 cedis per month]

A major complication of the financial burden of the disease is when marital conflicts exist between the couple or they are divorced. In such situations the mothers of the children expect that the fathers will bear the full cost of care and would therefore bill the men for every expense. The inability of the men to meet financial expectations results in lots of bitter exchanges between the two which ultimately affects the optimal care of the

child. Such fathers get upset and would not want to see the mothers at all. They therefore resort to proxies to determine how their children are doing and to send money across for care. Most often the men feel the women do not appreciate their efforts. F 16 presented a typical scenario of a relationship gone sour and the effects it was having on the child:

“Hmm!! This is a major problem for me. [...] I think she does not appreciate the cost implications of caring for the child. It is true that when the child is sick it is a worrying experience (Implication of statement--- but the mother assumes that as soon as the child is ill she must go to hospital). [...] My expectation is that the mum will send her to the hospital so that I would receive the prescription form and purchase the drugs. In the course of the sickness, if the mother and I should break communication for just a short while, she gets annoyed and insults me anyhow and talks a lot. That attitude hurts me so much. I care about the child and would like to see the child well”.

Strained marital relationships raise gross implications for care of children with chronic conditions such as SCD. In the context of the Ghanaian health system where self-financing seems to be the main available option for now, it is important that financial support systems are explored and institutionalised for families with SCD children who cannot afford care. Such a system will need a combination of conventional loan schemes and traditionally acceptable means of recouping monies borrowed. Another strategy is to ensure that families with SCD children all enrol into medical insurance schemes to cover the cost of care.

Another important challenge fathers described was the unpleasant encounters with health care professionals in the care of their children. This often arose when fathers were in disagreement with the course of treatment, not permitted to know about the condition or they had a feeling that their children were not receiving the best of care. Medical mismanagement was reported as common, right from diagnosis of SCD among the children to care on admission. For diagnosis, there were some (4) of the fathers who had

to report to hospital for several years with acute and frequent illness in their children before they could be diagnosed with SCD [F7]. Another reported site of disagreement with health professionals was around blood transfusion. F16 recounted his experience with doctors:

“I remember my daughter going through that. I used to resist blood transfusion; pleading for blood tonics rather but this was unacceptable to the doctors who requested that I discharge my child if I would not allow the transfusion. So I gave up. I was not happy with their reaction though because I was convinced there were medications which could play the same function. But I gave up and since then, I just allow it if they make that request. I think she had been transfused about three times”.

F 28 also stated:

“I don’t know but they keep prescribing drugs for the baby. I don’t know why these professional are doing this” [F28]

And F12 argued:

“To me I think it would be good for fathers to come to the hospital. But for me I blame the medical people for our lack of involvement in the hospital care of our children. Imagine that as a father of a child, I need to know about my child’s condition so I can better care for him. But when you attempt to pick the child’s folder to read its contents you are told to put it down. I remember there was another time that my second son was not looking well. There was a doctor living near our house who saw it and advised us to take the child to the hospital and we did but he never explained the condition to us. Why should I go to the hospital for these people to belittle my intelligence?”

It is evident from the accounts of the fathers that most of the encounters resulted from little or no communication between the health care professionals and themselves. There is a clear lack of understanding between the positions each one had assumed, resulting in friction and a consequent aversion on the part of the fathers to the hospital. Health care professionals are known to assume expert positions in most discourses on disease, thereby giving little opportunity for clients to share their feelings and their thoughts about the condition. In essence the patients, or in this case the parents, may feel powerless in decision making about their relation.

Since SCD is a life-long disease needing the attention and cooperation of both the medical professionals and family members as a working team in its management, it is essential that national SCD programme inculcate team-building as an integral part of management. This is certainly a challenge in a country with a very high doctor to patient ratio ranging around 1: 10,000 in urban areas and 1: 14,000 in rural areas (partnershipvolunteers.org/Ghana, 2005) and where doctors are often in a rush to see over 100 outpatients in a day.

Amidst all the pain and challenges of nurturing an SCD child, the fathers had hopes beyond the horizon and talked about what they aspired for their children. The next section gives an account of their hope for the future.

‘They call him doctor’ and ‘They are supportive’: Beyond the Horizon of SCD and Family Relationships

So far evidence from this study has shown that fathers affected by SCD interpret and make sense of the illness situation in their children within the social context they find themselves. They are also continually engaged in a process of construction and reconstruction of their perception of the disease as a consequence of interplay amongst their socially ascribed roles, financial status, experience with the disease, medical knowledge as well as social reactions to the disease.

In the face of all these complexities is the aspiration of the fathers that their toil would not be in vain and that the children will survive into responsible adulthood. As they look beyond the horizon, fathers give accounts of their best and bitterest experiences with SCD, family reactions to the birth of the child, their evolving concept of the child as s/he grows up and what is in the future for them. These features have been described in the course of this section.

Best and Bitterest Experiences with SCD

The notion of best or bitter experience with SCD struck different chords among the fathers. Nine fathers felt that there was nothing good about SCD and that its encounter is full of pain and trying moments as described by F22 below:

“Hmm, SCD happiness? Oh no! What about it brings happiness? Sometimes my son does things that disturb me a lot. For instance about 2 years ago, he was admitted to KATH and whilst on admission he will send people to buy pethedine from outside druggist for him to inject. Because of that he was discharged prematurely. And even after those 12 days on admission I had to pay a huge bill. Hmm! As for SCD there is no happiness”.
[F22]

Fourteen fathers felt there was something pleasant to share about SCD. The children of two fathers were so young that they had no experience to share. The rest of the fathers did not have the opportunity to share their best experiences because that question had not been incorporated into the interview topic guide at the time of interviewing them. It seemed that each father who answered the question had a different reason to share. Responses to best experiences were very diverse but could be grouped into health service provision, knowledge on SCD and role modelling.

On knowledge on SCD, fathers talked about being happy to know that it is possible for SCD patients to live into adulthood, and that inheriting SCD was through no fault of the child. That made it bearable for them to give support to the child when in painful crisis because then it is an opportunity for them to render propitiation for the suffering of the child. In a way they were saying “*We are sorry to bring all this suffering on you: Is there any thing we can do to make life bearable?*” They were also happy to know that would-be-couples have the opportunity to check their blood for sickle cell status to help them make informed decisions. Education at the SCC was of great encouragement to them because it helped them to understand the disease better. Furthermore, on the issue of health service provision they reported that the availability of clinical care services was of tremendous resource to them because it saved them from having to join long queues at the out-patients clinic for care.

Role modelling brought pleasant feelings to the fathers who have had the opportunity to see other people with SCD make it in life. F18 had this to share:

“I know somebody who is a medical doctor and has sickle cell. So I feel encouraged so see his siblings call him doctor, doctor. It is encouraging and gives me hope”.

Role modelling is a possible approach in patient and parent interactions as a means to promoting positive living and a desire to achieve among patients. The researcher had used this approach during her experience as an Education Coordinator on the Newborn Screening Project in Ghana through local conferences and seminars. The challenge though is getting exemplary role models (those who have excelled in their area of expertise) to publicly share their experiences with larger audiences. Such reluctance may be attributable to first, a feeling of ‘not wanting to tempt fate’ in case after such public

declaration they become seriously ill, and second, a reluctance to be defined by their illness state rather than by their achievements. Suitable avenues will need to be explored to encourage such role models.

In contrast, bitter experiences with SCD were reported to be associated with complications of the disease and its related problems such as:

a. Painful crisis (watching the child go through painful crisis and feeling so helpless),

“My worst experience has been with crisis (Note: though question was asked second, he answered it first. It seemed difficult for fathers to say what their best experience has been). They pause to reflect on the question before answering). It’s been worse because it is hurting to see your child go through so much pain when you have given all the medications needed and your child gets no better. It is difficult to watch your child suffer”. [F9]

“SCD is full of pain and frustration. Everyday this child is sick. Even today she is ill. Today you are called, three days after you will be called again. Oh! There are times you just have to sigh over these things [.....]. In fact there is no happiness in SCD. There is no occasion that I can remember that brings me pleasant memories to say something good about SCD. No there is nothing to accept as good. Some say SCD patients are brilliant but I don’t accept that because non-SCD children are also brilliant so it does not make them an exception. No, there is nothing happy about SCD. It is pain, frustration, disappointment, sadness”. [F16]

b. Cost of care (looking for money to meet cost of care)

“Erm, for that I will say finances. SCD is a big financial drain. Money that you intend to use for something else developmental always ends up paying for SCD bills. You can’t begin any project. You have to save that money for emergency situations. It is a worrying situation but what can you do” [F17]

c. Life span (anxiety of not knowing if the child will live or die),

“It is the hearsay that such children do not live long that sort of bothers me. I don’t know what is in store” [F13]

d. Frequent illness (child is always sick and spending sleepless nights to give care),

“When she is ill and you have to spend sleepless nights attending to her in bed is a worst experience because during the day, you go through your routines that drain you of all energy only to come home to stay up all night” [F19]

e. Breakdown of marital relationship (destroys love and care father has for mother),

“What hurts is that SCD has destroyed that love and care I had for the woman because she did not tell me initially that she had SCD” [F20]

f. Death (loss of children),

“Mine is the experience of losing my son (long pause). I will like to share this with you though it is difficult for me. It hurts me so much and I seem not to be able to forgive myself. I had borne his sickness all his life but on that day, at the point when he needed me most I was so tired I could not help. He died in the night (father cries)” [F7]

g. Notion of child suffering through no fault of his (bearing the brunt of what the father and mother did)

“SCD is inherited through no fault of the child. Complications arise without warning and the child suffers so much. Our Government has not done much for these children” [F7]

h. Poor appetite (child does not eat much) and confinement to bed in times of illness.

“My child would not eat and I don’t know whether it is like that with everyone of them. When she refuses food and you force her she would spit all out. She keeps getting weaker and weaker. I am praying that things will improve for the better” [F28]

“I recollect times of great depression as a SCD patient myself. When I am incapacitated due to illness I get so sad. It grieves my heart to be confined to bed when my contemporaries are going about their day-to-day plans. I am a hardworking man and I get filled with sorrow when I am down with illness” [F6]

A reflection on the narratives of the fathers on both their best and bitter experiences shows a close linkage with the variety of lay discourses (social beliefs) described in Chapter Five. Obviously, the lay discourses about SCD as a source of financial drain, cause of early and recurrent death, poor and delayed growth, and as a bought disease are social constructs genuinely derived from the experiences of families. These findings further explain the stigmatising attributes of SCD, and its perpetuation in society. This

implies that programmes designed to support families in positively living with SCD will need to adopt strategies that will break the cycle of pain and bitterness that parents experience. Without that, SCD will continue to be stigmatised and parents will not be able to openly discuss their children's conditions, nor argue for the provision of better care. Furthermore, this would permit Governments to provide only mediocre services, and this poor level of service will itself limit the potential of the SCD patient to grow up healthy and become a responsible and economically productive citizen. The resultant effect will be a continuation of the dependency status of the chronically ill patient such as that of SCD.

Family Relationships

The reactions of both nuclear and extended families to the birth of a child with SCD are very important in determining the degree of acceptability of the child in the family and go a long way to also strengthen or weaken the marital ties between the father and the mother. Another important factor is the ability of the father of the child to resist any negative reaction from the family and to exhibit a positive protection over the affected child, which in the end promotes family acceptance of SCD and commitment to support in the care of the child.

As reported in the literature (Hill, 1994) it is not uncommon, as part of West African cultural values, for the extended family to play significant roles in childrearing. Most often, they are known to offer 'child-keeping' support to the affected family thereby facilitating their ability to attend to competing responsibilities. Consequently, the

researcher was interested in finding out how families reacted to the birth of the SCD child, how supportive they have been and the extent to which the birth of the SCD child has affected the marital relationship between the couple. The following describes relevant findings and what the implications are for the development of health and social care programmes for SCD in Ghana.

It is worth recalling that in Chapter Five the researcher reported that fathers would only share information on the diagnosis of disease to significant others who they felt had something to offer in terms of moral or social support. Consequently when asked about family reactions, more than half of the fathers interviewed (18) reported that it was common for their parents, siblings or parents-in-law who are made privy of their children's condition to be supportive of them. The support was due to family members being familiar with the disease as affecting other family members, or by contrast, because they did not know what the disease was all about. Some were also described to be supportive because they felt whatever it was had already happened and therefore there was no point in criticising. F2 recounted:

“They are rather supportive and try to encourage me so I don't get discouraged. My mother-in-law often makes statements like “Oh! This child's illness is real problem for you. Do send her for prayers so God will protect her”. I do assure her that we pray everyday for God's protection. My parents also do encourage me”.

F29 also said:

“Oh! What doesn't my sister do for [name of child]? She is a nurse so she is very cooperative. She buys shoes, clothing and what have you for him. I don't have any problem with my family”.

The group of nine mothers who participated in the focus group discussions corroborated these findings. Another reason for family support was the interest to encourage the couple

to bear more children to increase the extended family size. This was evident in the F4's recall:

“No. No one in both families interfere with our marriage. They don't say any negative comments. My in-laws do not have a large family so they are even happy that we have 5 children. My wife's aunt had no child so even when I decide not to have more she virtually begs me to give their family more children. She even said that when my eldest daughter graduates from high school she would adopt her. They are happy with my children and even she sends them dresses at Christmas”

The assertion by F4, an assertion supported by M4, provides valuable information on the degree of influence that the extended family may exercise in decision making on family size. In the case of M4 she sees herself as the only female among her siblings and therefore has an obligation to have more children for the matrilineal family. Therefore if the husband decides that they would have fewer children because of the SCD child, then she feels she would be forced to divorce and remarry another man.

Their situation presents a case of what the researcher would, to further develop Bury's (1982) notion of biographical disruption, call 'procreative disruption', which could have grave consequences for childcare and welfare in circumstances where couples belong to low-income families and the promised source of support from the extended family proves virtually non-existent. Social support programmes aimed at providing services to affected families with SCD need to design an all-inclusive programme that takes into consideration the influence of the external family in decisions on family size and their implications for care.

On the other hand, the researcher notes that not all the fathers (4) were very much inclined towards soliciting family support or opinions on the care of their SCD children.

These fathers explained that they were not typically concerned about the reactions of the extended family and that it is basically their responsibility to decide how best to care for their children and how their marriage should run.

Most of the fathers (22/31) and mothers (7/9) felt that despite the birth of SCD children and all the stress that goes with it, their marriages have not been affected. They claimed that they tried their best to keep the family together and in times of illness they supported one another to manage the crisis.

"I would say I have gone in to marry and there is no turning back so far as I am concerned. I will not break my marriage because of the child. I don't know what my wife's perception is. I am not turning back."[F12].

But nine fathers and two mothers thought otherwise. They perceived that their marriages or relationships had been affected in the sense that the presence of SCD in the family resulted in occasional arguments with its resultant temporary strain in relationships. Other effects included financial stress, added burden in traditional roles, marriage separation and total break in relationship (5); a common occurrence among the fathers who had the children during courtship rather than under the auspices of traditional marriage.

A typical scenario could be described of M8, a mother of three children, all with SCD. The birth of these children had resulted in a big strain in the marriage but the husband has not been able to tell her outright that the marriage was over because of the traditional implications of that decision. Traditionally, he will be required to summon a meeting of the wife's family and that of his, justify his decision not to marry again, perform the rites to sever the relationship and provide a severance package for the wife. This has gross

financial implications for which most men without the means decide not to get involved with. Rather, they leave the relationship hanging, whilst they get involved in other relationships. Below, M8 reflects on her position:

“For me, my husband is actually not telling me to go. At the same time I can’t tell exactly what is happening with my marriage. It has brought about separation between the two of us. Even yesterday he said that if I like I can bring the children to him and I can go my way. Right now what am I going to do if I give the children to him. He says he spends all his money buying drugs for the children so he has no money to give to me to trade. I did not go to school so I cannot look for any office job. Right now we don’t even sit down to converse. When he sees me he is angry. I don’t know whether it is because I don’t have any work doing. Right now I am not happy at all. You know we are married so if he decides not to marry me then as tradition demands, he must return me to my family. This will mean him having to perform the separation rites which require money. As a result, he has refused to say outright that we are no more married. Its like whatever I decide to do with myself is up to me”.

In a tradition that fails to raise strong objections to unacceptable behaviour by men, and where the system of social services is not easily accessible to most mothers who are in the low-income status or are unemployed, some men may assume positions that are detrimental to family stability. Social support services for families affected with SCD need to develop a strong partnership with the existing social welfare network and support the building of a formidable team that can effectively manage such cases that might be referred to them.

Beyond the Horizon

So far in this chapter, the impact of SCD on the lives of the fathers and the few mothers interviewed have been outlined. This impact is diversely reflected in the expression of meaning to the diagnosis of SCD in their children, the process of resolution to accept the baby as a gift from God, the day-to-day management of the disease in the steady and illness states and the challenges they face with extending such care. Also recounted are

the family interactions that bring to bear on their decision making in childcare, support, family size and marriage stability. Beyond all this seemingly complicated pattern of expressing the meanings they attach to SCD is a hope that their children would survive as a reward for all the physical, social, and emotional investment into their care and existence.

Fathers affectionately described their children beyond the horizon of the SCD illness state and what plans they have put in place for the future of these children. They used phrases like: *“despite the illness I love him”*; *“he is a pleasant person everyone likes him”*; *“she is an intelligent and caring child”*; *“she is smart in learning”*; *“I love my child”*; *“he is hardworking and helpful”*; *“she is smart and I love her so much”* to describe their children. They also added that their children, apart from times of illness, are able to do whatever other normal children do so they are quite happy with that. Some expressed the view that their children have dreams and that they would do their best to help them to achieve the highest academic or occupational level that their resources could permit. The following illustrates some of the perceptions of the fathers interviewed.

“He says he will be a doctor so he has a lot of doctor friends. He has been able to strike acquaintance with the medical director at the military clinic and is able to walk to his office when ill”. [F30]

As a person she is very good at art. She can produce your portrait in no time. On the other hand she is very temperamental. With her gift in art it is my desire that she develops it to the farthest point and I am prepared to support her to attain that height. Whatever I can do to ensure her optimal health I will do to the best of my ability [F14]

At the background of their minds, they prayed that God will sustain them as fathers to be able to help these children realise their dreams to see beyond a life of illness and pain.

“For me it is my prayer that God will allow me to live to care for this child to my best ability”. [F28]

There were a few fathers who felt safer taking days one at a time and not hoping too far into the future. F9 noted:

“Well I don’t sit down to think too much into the future. You take the day as it comes. I rather pray that God will strengthen my son to be able to take the negative criticisms that people will make”.

These findings show a tendency to move beyond everyday expression of pain and despair to a position of hope and looking forward to relief from all the challenges they face. They take consolation in the fact that apart from the illness, the children are comparable to other children with character, affection, desires and dreams that must be nurtured. This implies that such a positive outlook could be harnessed as a tool for helping parents to reflect on the positive aspects of their children and to work at developing such potentials for the future of such children instead of nurturing a life of dependency.

‘My mother is there’, ‘It is not his doing’ and ‘I can handle this myself’: Coping Systems in Fathering a Child with SCD

According to Pearlin and Aneshensel (1986, cited in Hill, 1994: 156) coping is defined as “The things that people do in their own behalf to avoid or minimize the stress that would otherwise result from a problematic conditions of life”. Several commentators have indicated that for people to manage stressful situations, they need to employ the social

and psychological resources available to them to generate appropriate coping responses such as self esteem, money, power, social support and beliefs (Hill, 1994).

In common with other chronic conditions, assumptions that SCD is inevitably linked with recurrent bouts of illness and/or early death or stigmatization of the illness have been reported to cause high levels of stress among patients, parents and families. The researcher therefore sought to find out the variety of coping systems used by the fathers to deal with caring for their children with SCD. This section of Chapter Six describes the diverse sources of stress mentioned by the fathers and the coping responses they harness to deal with the stressors.

In the fathers accounts of the bitter experiences with SCD, they listed frequent illness, painful episodes coupled with the fact that the child was suffering through no fault of his, cost of care, perceived short lifespan of patients, experience of loss, compromised physical appearance of child, habits of food refusal and breakdown in marital relationships as major sources of stress in their lives as fathers of SCD children. Other implied sources of stress were frequent hospitalisations and blood transfusions, and the lack of availability of time to care.

To deal with these stressors, fathers reportedly harnessed coping resources such as social support, embracing the medical concept of SCD, money (seeking loans), self esteem (a feeling of 'I can handle this myself'), religion, positive framing of self and child, optimistic thoughts, sustaining good relationships and reliance on home maintenance

skills of wives (the ‘master carers’) to guide their responses to the stressor within the context they found themselves.

Social Support

The major coping mechanism available to the fathers was the use of social support services offered by their parents (predominantly mothers), that of their wives, siblings and friends. Their mothers and siblings often acted as reliable sources of care and encouragement to them in times of crisis. Some fathers (3) sent off their children to live with their grandparents because of the assurance that they would be better cared for.

“My mother is there to take care of them daily. When they close from school, we send them all to my parent’s house for the afternoon and we pick them up in the evening after close from work. Knowing them and my SCD child, if she feels that one of them is unwell, she just calls me on phone and I come over to see what must be done”. [F8]

“My mother supports us by taking care of him. He is in Accra with my mother. We decided that he won’t go to boarding school. All his siblings are in boarding but he is not so we can monitor him. For friends I don’t necessary get any support from them”. [F9]

“No friend or family member has been as supportive as my sister. We live in the same building and she is my director’s wife. The support I have been receiving from her has been very instrumental in caring for this child. However, I don’t go to her asking for money to buy drugs or something of the sort’. [F29]

Other means of support included supply of routine drugs by siblings and relations living abroad. Constant touch with relations through telephone calls and visits were also perceived as helpful and relieving.

Medical Model of SCD

Another important means of coping for ten of the fathers was the reliance on the medical model of SCD. By so doing, fathers fell back on the store of knowledge they possess through attendance at continuing education sessions on SCD held at the SCC and support

group meetings. With this knowledge they were able to clarify and accept the cause of the disease as genetic, and since an SCD child had no role to play in its inheritance, it followed that such a child could not reasonably be blamed.

The acceptance of the medical interpretation of the disease further justified their moral obligations to the child and facilitated their cooperation in childcare.

“I feel I need to be very vigilant on his upkeep, treat him well like all the other children and ensure his welfare. I know that it is not his doing to be born with SCD”. [F10]

“Let me use my son as an example. He has 2 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 at 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”. [F12]

“It is a chronic disease. The only thing is that when the child is ill, as apparent you must have time for the child and rush him to the hospital. You don’t have to be buying drugs indiscriminately. You must seek expert care from the hospital, usually when he is unwell. We go to the Government hospital near by for care then later to KATH. When he complains of pain, we put hot compresses on the affected parts and sometimes the child even reminds me of things I should be doing if the mother is not in the house”. [F18]

The medical concept of SCD was again instrumental in their understanding of basic complications of the disease and of what could be done as home maintenance measures.

The support extended by the health care professionals was also of tremendous boost to their morale as explained in the following statement:

“In the hospital the doctors are very supportive and understanding. Even when you are discouraged they comfort you. Sometimes they talk to you and ask questions about his care. That is a plus. I have sent the child to hospital myself twice and when she is on admission too I go there. The doctors have done well. [F16]

Furthermore attending the clinic also exposed fathers to seeing adult patients with SCD. This had the potential both to provide them with hope and to lessen any fear of SCD as F27 explains:

“The assurance that even mature people with the disease come over to the hospital for medication has given me hope that the disease is nothing to be afraid about”.

This has important implications for the advancement of people with SCD in Ghana, since the survival of adult patients is a challenge to the folklore that children with SCD will die soon.

However, the majority (21) of the fathers who were unable to seek direct access to information on the medical model of SCD relied on their wives as primary sources of information. Through their wives who attended SCC and support group regularly, they learnt about the disease and were receptive to the new knowledge. Though most of the fathers harnessed the medical model in its positive sense, a few (4) capitalised on what it had to offer to construct a meaning that justified their decision to break the relationship they had with the mother of the child. For instance, F3 recounted that though he loved the mother of the child, he felt there was no need to continue the relationship so they could avoid having more children with SCD.

“Since the birth of this child, I have been contemplating putting a stop to this relationship because we are both young and it is possible for us to meet future partners who can give us non SCD children. So we (myself and the lady) came to see Dr X. But in the course of the discussion, the lady did not seem to understand the importance of us breaking”.

The position adopted by F3 exhibits an example of the variety of means (both positive and negative) through which people gather the cultural resources at their disposal to construct meanings and coping responses to address the context in which they find

themselves. The actions by the four fathers interviewed raise important implications for genetic counselling in that, though the purpose of counselling is to help couples to better understand the disease and adopt informed choices, it is possible that the acquisition of knowledge will form the foundation for a succession of marital conflicts among couples. Such occurrences could tarnish the positive concept of genetic counselling within the Ghanaian socio-cultural context and negate its usefulness in the long run.

Money (seeking loans)

Knowing that in case of financial stress there were people they could turn to lend them money towards care of their SCD children constituted a coping strategy for four of the fathers. Much as they would not perpetually rely on borrowing to meet health care needs, they indicated that there were a few relations and friends they would consult for a loan. As we have seen, the financial cost of care for patients is a major factor that influences the meaning they attached to SCD and underlay the sense of depression, frustration and sadness they expressed upon diagnosis of disease.

“They give me loans that I pay later. My friends give little gifts of money once a while when he is sick. The association of support has been the SCD Association. They help us with blood donation and routine drugs such as folic acid and Paracetamol (acetaminophen)”. [F13]

Seeking out financial support to mitigate the cost of care for SCD patients, suggests that any SCD programme in Ghana that is to be successful will need to attend to this issue. Strategies to reduce the cost of care or set up systems of revolving financial access to parents of SCD patients could be explored for implementation.

Self esteem (a feeling of I can handle this myself)

Only one father reportedly used self-esteem as a coping resource at his disposal. To him, there was no point in seeking support, he would try to do his best but if anyone lent him support without him asking, that would be accepted. He said:

“I would say that I am a hardworking responsible man who tries to provide for the needs of my family. I do not rely on people to reach out to me. So I would say that I don’t necessarily look up to these supports. If someone has, and will like to support, all well and good. If none comes too, I will get on”. [F15]

It is possible that the adoption of self-esteem as a coping response by F15 was related to the context of traditional division of labour where the man had a responsibility to provide for the physical, financial and spiritual needs of his household. It may be that he presumed that seeking support from external sources was a defeatist attitude that he must try to avoid by ensuring that he was ever-prepared to cater for the needs of his family. Though this is a positive position to take, an over-protection of self-esteem could inhibit a need to request for a genuine support at a critical moment. This situation could in turn negatively affect the care of the child.

Religion

The majority (28) of fathers felt that, with the birth of a SCD child, they had no option other than to resign to what fate had brought them. In their reports, they resolved to accept the child by confirming their Christian faith. They also referred to the biblical assurance that children were a ‘heritage from the Lord’ and the ‘fruit of the womb’ or ‘a reward from God’. Consequently, they were assured that God who had given them the gift would provide for their needs. F8 noted:

“We made up our mind to accept the child as she is. That is what God has given us and we must accept her and take good care of her. We pledged to do our best for the child.

Besides the education we received from you people at the clinic served to encourage us to care for the child and to know that the child could live long to a ripe old age". [F8]

"When such things happen, what can you do apart from commit it to the hands of God? Some people with the disease have lived to 60 years some are 40 so you also pray that rumours such as that they die by 15 years will not be your lot". [F21]

Note that of the thirty-one fathers interviewed, thirty were Christians. It is therefore not surprising that their Christian faith was strongly reflected in the coping responses they chose in reacting to the birth of a SCD child. It represented an active coping strategy for the fathers affected and energised their belief in prayer and hope for God's grace.

Positive Framing of Self and Child and Optimistic Thoughts

Positive framing of self was evident among eight of the fathers. They expressed sentiments that, despite the fact that the child had SCD, s/he was their blood and offspring, and therefore they were happy to have the child. They reiterated their responsibility as fathers and their preparedness to ensure that they provided for all the needs of their children to the best of their ability. Examples of narratives to support these assertions are quoted as follows:

The child is my own blood, someone who will help me when he grows up into an adult. For him to be able to do that, it all depends on me as a father. I have to be committed and faithful to this child to provide all his needs. Even if I can't afford it, I can show love to him and he will grow up to appreciate it. When a child is born, he must be clothed, fed and kept healthy. There are so many things to do". [F20]

"The child meant a lot to me because I knew, whatever be the case, I have a responsibility to care for it into adulthood. So I was prepared to face any challenges that came my way in his upbringing". [F18]

They also translated the concept of positive framing to their children and tried to perceive the children as capable of achieving. They used phrases like *“despite the illness I love him”*; *“he is a pleasant person everyone likes him”*; *“she is an intelligent and caring child”*; *“she is smart in learning”*; *“I love my child, he is hardworking and helpful”*; *“she is smart, and I love her so much”* to positively frame the children. The notion of normalisation was also apparent as the fathers tried to defend their observation that the child was not always sick, and looked like any other child when in their steady states.

“As a person she is very good at art. She can produce your portrait in no time. On the other hand she is very temperamental. With her gift in art it is my desire that she develops it to the farthest point and I am prepared to support her to attain that height. Whatever I can do to ensure her optimal health I will do to the best of my ability”. [F14]

“For me it is my prayer that God will allow me to live to care for this child to my best ability”. [F28]

“He is like any other child. He goes to school, plays, carry out tasks assigned to him. The only thing that disrupts his routine is this sickness. When he gets better, life goes on. He is able to do everything as a normal human being. He is 6 yrs old. He knows he has SCD but does not understand it and does not perceive himself any different from his siblings”. [F10]

The use of strategies such as positive framing, optimistic thoughts and normalisation were often used to portray what they perceived as the strengths of their children and to raise awareness that they as fathers were very much in tune with their responsibilities and doing their best. It also served as an assurance to civil society that they had not neglected their children despite the high cost of care. They also hoped for a fruitful and longer life as fathers to enable them cater for their children to grow into productive members of society.

Sustaining Good Relationships

This was a strategy reported by a father as a means towards ensuring that any time he needed to ask for permission to be away from work due to illness in the child, he would be granted and would not have to lose his source of livelihood. He made conscious efforts to do his work well and to keep good ties with his employers. Another area of maintaining good relationship was with his family. He was aware of the need for regular blood transfusions for his child and therefore ensured through the maintenance of cordial relations he could call on his family to act as donors for the required blood type. F23 described his strategy this way:

“I will say the cordial relationship between me and my employer has been able to give me the peace I need to make me earn a living to care for my children. My family too have been supportive in getting replacements for blood transfused on my child”.

One could argue that such a coping strategy has a tendency towards over-reliance and ‘taking things for granted’. However it is clear from the narrative that he was cautious about his actions to avoid such a situation and any resulting falling out of favour with his family and employers.

Monitoring mastery: Reliance on home maintenance skills of wives

Hill (1994) suggests that one of the ways in which low-income African-American women cope with a child with SCD is through ‘achieving mastery’. In this study, the fathers implicitly recognised this achievement of the mothers, but they claimed the credit for monitoring, overseeing or checking this mastery was continued. It was common for fathers who were not regular attendees at the SCC to state that their wives were more informed about the home care of the children than they were, and therefore they relied on

their wives to care for the child by applying the knowledge gained from support group meetings and education sessions at the SCC. They explained this as follows:

“Yes. Now I can say through the education my wife is very skilful in the management of SCD. Since we adopted the advice and counselling given at the meetings we have not had any problems with the child for about 7 yrs now”. [F21]

“On such occasions, I let the mother take him to the hospital. Even though I may not go along, my mind and my heart follow them”. [F10]

“It is the mother who often cares for her when she is ill”. [F16]

They expected that with such knowledge the mothers or wives would be able to differentiate between simple illness and complicated situations so they could act promptly. This implied that the mothers acted as radars to sense the status of the children and to advice on prompt decision-making and action.

On the whole it can be stated that, fathers harnessed multiple coping resources such as social support, embracing the medical concept of SCD, money (seeking financial loans) and self esteem (a feeling of ‘I can handle this myself’) in dealing with stress arising from SCD. Other strategies included drawing upon religion, positive framing of self and child, optimistic thoughts, sustaining good relationships and monitoring mastery. These various strategies are resources for positive living that could be adopted and taught to families living with SCD so that they would be able to choose appropriate coping strategies that suit their particular socio-cultural circumstance.

*‘Teach the Men’, ‘Talk to the Women’, ‘Talk to the HCW’ and ‘Advocate’:
Recommendations for Paternal Involvement*

The previous section dealt with coping systems in fathering a child with SCD and described the variety of coping responses fathers employ in addressing the enormous stressors that arise in their day-to-day relationship with SCD. It also reflected the way in which fathers’ traditional responsibilities as breadwinners and heads of households influenced the type of coping responses they employed. In this final section the researcher describes the recommendations given by the fathers, mothers and specialist Health Care Workers (HCW) on aspects of improving paternal involvement in health care for SCD children, making the health care system better for managing SCD, and the type of social support services that could be set up for SCD in Ghana

Recommendations for Paternal Involvement in Health Care

Paternal involvement in health care is an emerging concept and consists of encouraging and integrating men’s role in improving uptake of health services by families and communities. This concept is at the heart of many reproductive health initiatives in Africa and other developing countries. It will be recalled that, so far in this thesis, a majority of the fathers have indicated that it was routine for the women to send their SCD children to the SCC whilst they ‘checked’, ‘ensured’, ‘confirmed’ and ‘directed’ the care of the child. It was also evident that the notion of traditional division of labour had greatly influenced the construction of these paternal perceptions, though it is worth noting the few (5) men who reported a more active participation. In addition to asking about the

meanings they attached to SCD and their paternal involvement in the care of an SCD child, the researcher asked what they recommend could be done to reduce the possibility of fathers absconding, to increase their involvement in the care of their SCD children and what approaches should be used in achieving such objectives.

Twenty of the fathers reported their perception that with SCD, there was a potential for some fathers to abscond from their families and their children. They said that lack of education, cost of care, negative lay concepts about the disease, lack of appreciation by their spouses and poor marital relations could be contributory factors to such situations. In their words they noted *'I think it is lack of education'*; *'I think some see it as demonic'* *'It is because of the speculations that these children die young'* *'Some men don't value children and marriage'* *'It is because the disease is a heart wrenching one'*. *'It is because of money'* and that *'The women do not talk nicely to their men'* *'The women do not disclose their SCD statuses'*. Three fathers also asserted an additional type of reason based on individual moral culpability, including *'sheer wickedness'*, *'irresponsibility'*, *'stinginess'* and *'negligence'*. F13 indicated the frustration of frequent hospital visits and hospitalisations with its associated cost and its potential to drive fathers to the point of absconding. He said:

"They run away because of cost: Everyday the child is sick: Today he is sick, tomorrow the same. Today he is in hospital, tomorrow out. It is the cost that drives them away."

These narratives have considerable implications for social policy. For example, cost of care, strained marital relations and negative lay concepts are recurring themes underlying most of the social impact of the disease on fathers and indicate the seriousness with which the fathers perceive its effect on them. Social policies aimed at working with

fathers to reduce such effects on them could go a long way in mitigating a potential situation where the health and social support service in Ghana will be faced with unsupported single parents (mothers) with no regular and sustained support for their chronically ill children.

In a related aspect, increasing paternal involvement was perceived as relevant and useful in maximising the benefit of emotional and psychological development of the SCD child especially. Therefore instead of absconding, fathers should be encouraged and supported in partnering with their wives, families and HCWs in childcare. They (21) asserted that there were three fold reasons why paternal involvement was crucial. These were: i) fostering mutual partnership and cost-sharing, ii) promoting cooperation with HCWs in care, and iii) improving parent-child bonding. Their specific reasons reflected in their own words were: *‘Teachings in the SCC helps the father to ask questions, meet the HCWs and allows for probing’*; *‘Creates in the child a feeling that s(he) is loved by both parents’*; *‘it is through the father and mother that the child was born’*; *‘sometimes the women are busy in the house whilst the men are less busy’*; *‘men would know how to care for the child when the woman is absent’* and *‘women need their male counterparts to ginger them up’*.

F24, in a sexist statement, noted:

“Yes it is important. The presence of the men facilitates quicker service. For instance after waiting for sometime without us being called, I went to enquire about it and I was assured that more of the cards are still in the queue so we will be called in due course. But a woman will often sit down waiting on end to be called”

His statement reflects a wider perception by some of the fathers in this study that men are the chaperones of women, and that without them women seem lost in what they can do.

Such comments reflect the wider gender order of contemporary Ghanaian society. The fathers draw upon what they perceive to be the 'natural' order of things in a manner that both distances themselves from direct physical and emotional labour, and reinforces their self-perception of their social positions as heads of married households.

On a more positive note, the majority of fathers showed enthusiasm about increasing paternal involvement and were cognisant of the benefit of this involvement to child care. Their statements implied the possibility of health and social service care providers harnessing the fathers' positive outlook in improving or sustaining their involvement in programmes associated with the family.

Furthermore, the fathers made suggestions on how they thought absconding could be prevented and paternal involvement increased and sustained in SCD childcare. The fathers suggested that though they themselves do not have the intention to ever desert their wives and children, they acknowledge that something needed to be done to ease the burden on fathers and to encourage them to remain, in spite of the challenges. They recommended four ways of dealing with this concern. The first was public education; second, instructing the fathers in SCD management at home; third, promoting better marital relations through teaching; and fourth, re-orienting HCWs in their relationship with parents of the chronically ill.

On public education, they suggested that educational campaigns should be mounted nationwide, especially in communities with minimal access to health care, to teach the

public all they need to know about SCD. It should also address the negative concepts about the disease, encourage parents to be supportive rather than give up. It should also try to gradually reduce stigma associated with it. Education should be channelled through the mass media such as television, radio, leaflets, newspapers and brochures. Interpersonal communication avenues such as churches should also be employed.

“I think education is the key. There are so many people in the church and through the pulpit or talks by invited guest we could get them to participate in child care. The radio is another powerful medium which reaches a lot of people so people can be educated to change their attitudes” [F19].

Second, teaching the fathers on SCD and its management was crucial to them. They believed that, though their work schedules often conflicted with their desires to participate in the clinic activities, opportunities could still be sought to increase their involvement through personalised letters, home visits, seminars and individualised meetings. F 14 noted:

“It all boils down to education. Education will go a long way. As I sit talking to you now, I have learnt a lot to enable me talk and advise other colleagues should I meet them. Education helps a lot. Because what I have learnt at KATH has been very beneficial. We as fathers who have benefited from the education programmes can be advocates for increased paternal participation in childcare”.

Fathers also suggested that topics of interest to mutual partnership in the care of the child should be added to the teaching and both partners should be invited to attend to ensure uniformity in processing information received.

They also had a strong feeling that for their sustained interest in childcare, their wives and partners had a big responsibility to play in improving marital relationships. They complained about the attitudes of their wives and felt that their wives should ‘sweet talk’

them into doing what they had to do rather than the use of harsh words which only served to enrage them. A few of the comments were as follows:

“It mostly depends on the woman. If the woman will handle the man with love, is obedient and humble, the man will do whatever she says. If there is love in the marriage there is nothing that cannot be done”. [F15].

“The women also need to be educated to know that the idea that the man has a child does not imply that he should bear all cost of care. If the woman can help she should. The most important thing is for the couple to be of one mind so they can care for this child in peace. With this atmosphere, if the man hears the child is ill he can opt to take the child to the hospital. But if that is not the situation and the man after doing all these will be expected to bear all the cost then there must be division of responsibility. I pay for all cost by working to raise the money and you give all the care”. [F16]

“The way we talk to each other as fellow humans is very important. If you are rash with the man, you will not get any good co-operation, though he is very much aware he must provide and participate in the childcare. If you the mother is very troublesome and abusive, the man will desert you. What if he leaves town and you don't see him anymore? What can you the mother do? But if the mother is patient and cooperative definitely the man will support” [F20]

These reports again portray the tendency for the fathers' interviewed to hold their wives or partners responsible for their (fathers) actions instead of perceiving the issue as having equal relevance to the two of them. This finding brings to the fore the feeling that as men they should be revered, pampered and encouraged to do what they do.

In teaching partners to participate in health care of their children, it will be important to consider how these male perceptions could be addressed and re-directed positively without creating conflicts. The traditional focus of men will need redirection to include roles as care-givers as well as breadwinners and heads of households. However, at present some of the father's narratives position women as responsible not only for the direct care of the child with SCD, but also for nurturing the father's care of the child, arguably placing a double burden of responsibility onto the woman. Part of the challenge

in initiating change will therefore also be to persuade Ghanaian fathers to take responsibility for their own emotional work and child care.

The relationship with HCWs was another factor fathers felt needed to be addressed if increased paternal involvement was to be achieved. Some fathers narrated incidents with HCWs which served to demoralise them, thereby undermining their interest in participation. F 12 said:

“ . But for me I blame the medical people for our lack of involvement in the hospital care of our children. Imagine that as a father of a child, I need to know about my child’s condition so I can better care for him. But when you attempt to pick the child’s folder to read its contents you are told to put it down. You see all we get from the hospital are prescriptions upon prescriptions. So why go”

F20 suggested:

“Besides if we can get health workers visiting us as you are doing now and sharing some knowledge with me it will also go a long way in encouraging fathers”.

F 23 also added:

“It is possible for the father to learn so many things about the child and the condition that he would not need to rely heavily on the mother for everything. Just as you called me and we were able to agree on an interview time and place, I believe it is possible for health workers to involve fathers”.

These comments suggest the relevance of reorienting HCWs in the concept of client-oriented care in quality assurance. The use of strategies that includes parents in childcare could be employed to improve on relationships. Notions of professional expertise and power need to be revised to embrace lay participation and contribution in health care delivery.

Conclusion

This chapter on the 'Social Impact of SCD on Fathers' has looked broadly at the social meaning of fathering an SCD child, extending care to SCD children, challenges associated with paternal care, examined the wider horizons of SCD beyond immediate family relationships, and considered the coping strategies fathers adopt in dealing with the disease.

Findings have shown that fathers exhibited two main reactions to the diagnosis of SCD in their children: that of nonchalance or extreme worries or shock. The majority greeted the diagnosis of SCD in their children with a good deal of uneasiness, sadness, discouragement, apprehension, depression or withdrawal, and a presumption that their children would not live long. For those who exhibited nonchalance, it was apparent that their reactions did not imply lack of concern for their children, but rather reactions stemming from that of a past experience with the disease or minimal insight about the pathology of the disease.

Much of the evidence in the discourses of the fathers, both for those who showed nonchalance and those who exhibited negative reactions to the diagnosis of SCD, strongly suggested a direct relationship between the level of reaction to diagnosis and individuals' perceived knowledge about the disease, previous practical experience with the disease, or what has been said by the laypeople, and even in some instances qualified, health workers. The lay discourses on the disease proved to be a collection of subjective theories propounded by people who have had bitter experiences with the disease whilst

those with uneventful experiences perceived it in a different light. These findings suggest the need for educational efforts in SCD programming to design individualised education sessions tailored to meet specific needs of fathers within the socio-cultural context and perceived concepts about the disease.

As part of the process to resolve their grief, fathers gave responses that reflected a pattern of individualised process of grieving characterised by blaming, confirming, justifying and accepting before arriving at a resolution. The nature of this resolution commonly suggested a degree of paternal dependence on the mothers of the SCD children for their optimal care, since the fathers felt they had a responsibility to provide the financial needs of the household whilst the mother or wife had a duty to care for the child.

This finding underscores the need for creating co-operation as part of genetic counselling between both parents of a SCD child in order to promote optimal care for the child. In pursuit of such a goal, it is important that the traditional division of labour is brought into context and its strengths harnessed in a way that ensures parental commitment in whatever circumstances they find themselves in: that is irrespective of whether the responsibility is complicated by work, separation in marriage or divorce. The expressions of fathers on the extension of care to SCD children portrayed the emotions they go through as part of their experiences in parenting a child with SCD. They covertly expressed feelings of fear, uncertainty, frustration, depression and pain. Their reluctance to be explicit in stating their emotions was explained to be due to traditional gender related modes of expressing pain common in most African cultures.

It was also evident that, depending on the social context within which a couple found themselves, they reconstructed and redefined their roles within socially acceptable limits to accommodate the child. Again, findings showed that in extending care, fathers felt the mothers had limits to their capabilities in childcare and therefore expected them to keep in contact with them as fathers, who conceived themselves as the heads of the household, for the right decisions to be made. Such findings suggest that it is important for programmes geared at increasing paternal involvement in health care for SCD patients to aim at harnessing the concept of men as partners in the care of the children. This could be done by re-branding the notion of traditional division of labour in a way that portrayed the couple as partners who supported each other in child care, and who were capable of constant negotiation on roles emanating from their social context, rather than a stiff adherence to traditional roles.

Challenges ranging from lack of time to accompany their children to hospital, and financial problems coupled with marital conflicts were found to be associated with caring for children with SCD. On the subject of finances and marital conflicts, findings suggested that lack of finance was a major obstacle to accessing health care for the SCD patient. Most of the fathers, especially those who had had experiences with frequent bouts of ill health among their children with SCD, described painful experiences when trying to source money for health care. Some had to sell their personal effects to raise money. Other challenges included unpleasant encounters with health care professionals and difficulty in accepting the physical appearance of their children described in their

own words as having knotted and contorted features (*woayε ndwedwendwendwe*’ in Twi)

Since SCD is a life-long disease, needing the attention and co-operation of both the medical professionals and family members working as a team in its management. It is therefore essential that national SCD programmes inculcate team-building as an integral part of management. This is indeed a challenge in a country with a very high doctor to patient ratio ranging around 1: 10,000 in urban areas and 1: 14,000 in rural areas

On the other hand, fathers could recall some positive experiences. These were diverse but could be grouped under health service provision, knowledge of SCD and role modelling. This was in contrast to the bitter experiences with SCD reported to be associated with complications of the disease and its related problems such as painful crisis, cost of care, perceived short life span, frequent bouts of illness, breakdown in family relationships, loss of children, notion of child suffering through no fault of his and lack of appetite in the child.

Findings further described how SCD is stigmatised, and how this stigma is perpetuated in Ghanaian society. It is evident that programmes designed to support families in positively living with SCD will need to adopt strategies that will break the cycle of pain and bitterness that parents experience. Without that, SCD will continue to be stigmatised and also Governments will continue to provide mediocre services thereby limiting the potential of the SCD patients to be productive citizens, in turn perpetuating the dependency status of the chronically ill patient such as that of SCD.

Another important aspect of the social impact of SCD discussed was the coping strategies used by fathers of children with SCD. Findings indicated that to deal with stressors, fathers harnessed coping resources such as social support, embracing the medical concept of SCD, money (seeking loans) and self esteem (a feeling of I can handle this myself). Others strategies included religion and, positive framing of self and child, optimistic thoughts, sustaining good relationships and reliance on home maintenance skills of wives (considered the ‘master carers’) to guide their responses. These variable strategies are resources for positive living that could be adopted and taught to families living with SCD so that they would be able to choose appropriate coping strategies that suited their particular socio-cultural circumstances.

The last section of the chapter outlined recommendations for paternal involvement in childcare. Through the discussions, it was established that pressures on fathers included a lack of education on SCD, negative lay perceptions on SCD, poor marital relations and cost of care among other factors. Findings also suggested that traditional notions of gender roles in care giving, attitudes of mothers and HCW and lack of education on SCD contribute to the minimal levels of involvement of the fathers.

Key recommendations provided to address the concerns raised involved four key areas, including public education; teaching the fathers about SCD management at home; promoting better marital relations through teaching; and re-orienting HCW in their relationship with parents of the chronically ill.

In the next chapter, the researcher focuses on discussing all the findings of this study in the light of existing literature on SCD, and in the context of traditional customs of Ghana in the areas of marriage, childbirth, childcare and the household division of labour. Other areas for comparison with the literature include the concept of health and illness, social reactions and lay discourses on chronic diseases and coping strategies in the care of the chronically ill.

CHAPTER SEVEN:

DISCUSSION OF FINDINGS WITHIN GHANA'S TRADITIONAL CONTEXT, SOCIAL MEANINGS OF HEALTH AND ILLNESS, AND SOCIAL REACTIONS OF FATHERS TO SCD

So far, the researcher has been looking at the contextual factors that influence fathers' perceptions on marriage, gender roles, having a child with SCD, the meanings they generate concerning the disease, and the underlying basis for those meanings. The researcher has also examined the myriad social and emotional effects of SCD on fathers and the coping responses they draw on to deal with the stressors. In this particular chapter, the researcher's interest is in shifting attention to discussing all these findings in the light of available literature, conventional medical knowledge, current health service provision in Ghana, and the situations in both the UK and the USA. Within this framework, the chapter has been laid out in three sections namely i) context of traditional courtship, marriage, children and family division of labour ii) the social meanings of health, illness and SCD iii) the social impact of SCD on fathers.

Context of Traditional Courtship, Marriage, Children and Family Division of Labour

Stages of traditional Ghanaian marriage

Evidence from the analysis suggests a particular context within which the Ghanaian marries. This includes the stage of courtship, during which the prospective partners study one another to convince themselves that they are a perfect match; the stage of

performance of the knocking rites, to signify to the girl's family that she is being courted by a particular man and that all things being equal, he would marry the girl. Next is the stage of traditional marriage, where by the giving of a bride-price the woman is socially recognised as the wife of the man.

These findings are supported by Kuada and Chacha (1989) and Salm and Falola (2002), who in their respective accounts describe marriage as an important unifying rite of passage that brings two families together and honours the couple. Kuada and Chacha note the initial step of the relationship where the man looks for a suitable partner and informs his relatives. Seeking the partner involved a process of learning to know the woman and deciding on her suitability. This process was what was referred to as traditional courtship in this study. The stage of knocking confirms the work of Salm and Falola who describe it as a meeting to seek consent from the woman's family and to notify them of intentions to marry. However, none of these commentators used the terms 'courtship' and 'knocking rites' to describe these stages probably because these are transient stages towards marriage and not conceptualised as periods of much significance in the Ghanaian tradition. However, findings of this study show that these are significant and distinct stages in marriage worth attending to as much sexual activity takes place among prospective partners. These stages should be critically considered in any programme targeted at providing services to couples. These include maternal and child health services more generally, as well as screening and counselling for haemoglobinopathies more particularly.

On the issue of the actual marriage, this study revealed that civil marriage, though an optional stage, was highly recommended and commonly practiced among the Pentecostal Christians because it was commensurate with the ethos of their denomination. Luginaah et al. (2005) note the potential of religious organisations to influence people's values, beliefs and norms and direct uptake of preventive services by its congregation. In a related discourse, Van Ness (1999) and Coyne-Beasley & Schoenbach (2000) argue that religious-based social programmes are more effective in some populations than programmes provided by government. These statements may explain the commitment to civil marriage expressed in this study. Findings in this study also showed that sickle cell screening was integrated as part of counselling sessions in preparation for civil marriages, reflecting similarity with the findings of Van Ness (1999) and of Coyne-Beasley & Schoenbach, (2000). Religious beliefs and its ethos were therefore grounded in patterns of courtship and marriage among the people of Ghana. The degree of influence of ones religious belief on values and lifestyle was dependent on the Christian denomination one belonged to. Churches are known to have both extensive and intensive powers that affect behavioural patterns of its members (Garner, 2000).

Genetic testing and counselling

In general, genetic testing for sickle cell was established through this study to be a concept alien to Ghanaian couples, though it is assumed by various authors (Anionwu, 1993; Atkin & Ahmad, 1998) in Western Countries to be a "good thing" for carrier status to be widely known by people in the community before having a child or entering into marriage.

Genetic testing and counselling were perceived in this study to be a recent concept introduced into selected churches (Charismatic and Pentecostal) for the benefit of their members and were not therefore practices familiar throughout Ghanaian society. Currently, there is no national health policy that commits prospective couples to test their carrier status. However these selected churches, with a perceived obligation to protect their congregations, have instituted pre-marital testing as part of their counselling sessions for marriage. It is believed that the upsurge of HIV/AIDS in several countries strongly influenced and contributed to the institution of mandatory testing as part of measures to curb its spread (Luginaah et al. 2005). Testing for SCD in Ghana by selected churches has become a mandatory addition to that of HIV/AIDS, since it was seen to be blood-related and, by extension, obligatory for the prospective couples to know each other's status. Though testing was perceived mandatory in Ghana, marital decision-making in the face of trait status remained the prerogative of the prospective couples whilst the church dissociated itself from the consequences of such decision-making. This means that in the case of SCD, though testing may be mandatory, marriage among known traits would not be necessarily prevented. These findings are consistent with that of the Greek Orthodox Church in Cyprus, where the church will not sanction the marriage unless both partners have been tested for beta-thalassaemia trait and present a certificate of testing (Angastiniotis, 1992). On the other hand, there are differences in the Ghanaian and Cypriot context in relation to service availability and utilisation and therefore present a challenge for SCD programming. First of all, the Cypriots have an organised national programme on thalassaemia management where cost of care is partially borne by

Government. Second, Cypriots have access to prenatal diagnosis and counselling and third, mandatory testing exists for every couple requiring a church marriage. Unfortunately the Ghanaian population do not have access to such provisions.

Furthermore, mandatory sickle cell testing is limited to the Pentecostal and Charismatic churches, thereby limiting the total number of people who eventually come to know their carrier status before marriage. In this study, the majority of the fathers did not know their status before marriage and, even in marriage, some had still not been tested despite the fact that they had children with SCD. This was because testing was uncommon and not routine in their churches at the time of their marriage. Second, Ghanaians do not have access, at least within Ghana itself, to prenatal diagnostic services to support and provide alternatives for reproductive decision-making. Third, public education on SCD is limited to the cities with specialised services for patients, thereby leaving the larger population uninformed about SCD and the benefit of pre-marital testing. The case of Cyprus provides one model of premarital counselling and testing with faith-based organisations as one of the key players, though there remain important differences in context between Cyprus and Ghana.

In a related discourse, researchers have argued that it is common for faith-based organisations to perceive public health issues such as HIV/AIDS, and one could argue by extension SCD, as important to their congregation and therefore recognise the need to adopt measures that protect its members rather than rely on governmental initiatives. Such measures have included education sessions, screening and support programmes

(Elifson, Klein & Sterk, 2003). On the other hand, such faith-based organizations have been criticised for requesting mandatory testing which tended to raise questions of human rights, an issue central to the *International Covenant for Civil and Political Rights* (UNAIDS, 1998). This states that “*No one shall be subjected to arbitrary or unlawful interference with his privacy*”; thereby making it unlawful for churches to make it an obligation for members to undergo genetic testing.

This widely acknowledged criticism, and pressure from national programmes, has resulted in a paradigm shift where churches now focus on ‘voluntary testing’ (though churches use subtle, but still coercive, language that pushes members to accept testing) as a means towards protecting those who are HIV negative from those who are positive. These findings offer invaluable lessons for the design of genetic testing programmes in Ghana. They suggest the need for integration of churches in service delivery in a way that ensures increased uptake of such voluntary testing, but within international rules and regulations.

This study also revealed that sexual relationships exist among would-be-couples, and that these may culminate in marriage, childbirth or children born out of marriage. The factors that influence decision-making leading to marriage were found to be contextual and reliant on a complex interplay of the woman’s attitude, beauty, readiness of the man to marry, religious beliefs and the presence of an unplanned pregnancy. Where children were born out of marriage, there was the possibility that the would-be-couple would not eventually marry. Marriage was the approved environment within which children were to

be born and nurtured. Findings on pre-marital sex are in contrast to traditional expectations where ideally the newly married woman joins her husband with pride and deep satisfaction for her moral uprightness as a virgin (Kuada and Chacha, 1989). Attitudes to pre-marital sex have of recent times been extensively radicalised, with globalisation to making it more acceptable (Kuada and Chacha, 1989; Hendrickx et al, 2002) though African men would continue to feel proud to have such women as wives. Changing social perceptions of pre-marital sex may explain the presence of children born out of marriage in this study.

This serves to further clarify attitudes of some fathers in the study who were expected by their religious values to abstain from pre-marital sex but ended up with unplanned pregnancies with its consequent rush to marry in order to cover up and avoid sanctions from their churches. It is therefore important that any genetic testing, counselling and education programmes are widely targeted at all sexually active age groups such as youth in senior primary to those in tertiary institutions as well as single parents and couples. Findings of this study strongly suggest that universal screening may certainly be the option for a country like Ghana where twenty-five percent of the population are traits (Ohene-Frempong & Nkrumah, 1994; Konotey-Ahulu, 1991). Fortunately, Ghana will not need to start a new model. There are several lessons to be learnt from the pilot newborn screening programme in Kumasi, as well the UK and USA where current screening programmes continue to be reviewed and critically appraised (Anionwu, 1993; Dyson, 1999; Streetly, 2000; Anionwu and Atkin, 2001; Ohene-Frempong, 2001; Dyson, 2005).

The birth of a SCD child in context

This study examined the perceived acceptability of the birth of an SCD child in comparison to childlessness, and findings showed that children were perceived as crucial to the survival of every marriage and, as with low-income African-American women (Hill, 1994), women would prefer a child with SCD than not to have a child at all. It was also found that couples' prior knowledge of their trait status would not prevent them from having a child if married but may influence their reproductive decision-making on the number of children to have.

These findings, consistent with those of several anthropologists, have underscored the importance of child-bearing in African societies in general and Ghana in particular (Ebin, 1982; Cornwall, 2001; Geelhoed et al. 2002; Richards, 2002). Having children is important to the African irrespective of age, marital status, educational level or occupation, because it proves ones fertility, marks an adult status, and creates ties of obligation between the women and men (Richards, 2002).

This study again confirms findings that knowledge of traits status through counselling does not necessarily change decisions to marry and have children (Shiloh et al.1995). However there are indications that perceived genetic risk may influence decision-making in terms of family size, with decisions to reduce family size made out of fear of cost of care for SCD patients, rather than this leading to any absolute avoidance of the birth of

children. This is because the Ghanaian society approves of and supports childbirth, but does not necessarily provide support for children (Kuada and Chacha, 1989).

Findings of this study also indicate that men's willingness and enthusiasm to accept responsibility for a chronically ill child was found to be dependent on the context within which the two met, courted and shared their personal genetic information of sickle cell status before the pregnancy occurred. Fathers who courted for companionship rather than with an intention to marry were very hostile to the idea of the birth of a SCD child (although not the child per se) whilst those who had an intention to marry may go ahead and marry out of love, or may withdraw due to perceived 'burden' of SCD. These findings are comparable to studies on minority populations in the UK and USA, which have documented negative consequences of genetic counselling and testing programmes. Such documented consequences have also been reported among Asian refugees in California; Bedouin tribes in Israel, and Pakistanis in Britain (Shiloh et al. 1995; Katbamna et al. 2000) and include stigmatisation and carer blaming. In some situations, the fear of repercussion of diagnosis by family members was so strong that carers would rather keep the degree of impairment as a secret. A common conclusion by authors, however, is that genetic testing programmes should focus on helping individuals and couples to make informed choices within their specific social contexts rather than aiming to prevent marriage between two carriers. This recommendation would seem equally appropriate for the Ghanaian context, where this research has shown that socio-cultural factors largely influence the social construction of normality, abnormality and negative lay conceptions surrounding SCD.

Further important evidence from this study was that childbearing and rearing was a responsibility defined traditionally by gender. Men were found to be responsible for spiritual leadership, health, education, clothing, shelter, food and nurturing combined with discipline, whilst women were responsible for childcare and housekeeping (Brannen and Nilsen, 2006). The pre-defined traditional gender roles influenced the way fathers related to their wives and SCD children, and confirm comments by such authors as Brown, (1996); Oware Gyekye et al. (1996) and Salm and Falola, (2002). Contrastingly, this study showed that a majority of the men adhere to their traditionally defined roles even in the face of support by the women in other responsibilities perceived as men's role. These Ghanaian men have persisted in their conventional roles despite changing family structures and global diversity in parenting where men have been reportedly able to negotiate and re-negotiate roles to accommodate the challenges faced by working mothers (Sunderland, 2000; Featherstone, 2003).

Very few men appeared willing to negotiate roles within the social context in which they find themselves. Where they do negotiate roles, it is purposely to fill an essential vacuum such as unavailability, feeling of incompetence, or lack of confidence by the woman rather than an understanding of the concept of greater equality in domestic roles: a concept perhaps more widely practiced in the contemporary West (Finch and Groves, 1983; Berhane et al. 2001). As a result, they assume those positions to save the family from embarrassment and avoidable cost. Nevertheless, evidence in the literature confirms that the institution of marriage has a strong capacity to positively influence men to take

their responsibilities seriously, such that children born in marriage are reported to have better care than those born outside it (Oware-Gyekye et al. 1996).

In the light of these findings it could be deduced that SCD children born within formal marriage have a better chance of receiving parental care than those born to divorced or separated parents. In any case, this implies that parental education programmes need to target both parents to maximise parental care to the SCD child.

Generally, findings on the traditional context of courtship, marriage, childbearing and family division of labour, raise implications for health and social policies in Ghana. First, in a country where twenty-five percent of the population are sickle cell carriers, Ghana needs a policy that will promote genetic testing among young adults even before they begin contemplating marriage, as there is a high chance of pregnancy occurring in any of the four stages of marriage.

Second, for those who seek testing at the point of marriage, the results may be a crucial determinant of the progression of the marriage arrangements, or a means towards seeking more information on SCD should the couple decide to marry anyway. As this study has shown, such decisions are made within a complex and wider social, cultural and gender relationships that cannot be overlooked in communicating genetic information. This therefore calls for the development of a comprehensive genetic counselling programme in Ghana designed to be culturally sensitive to various target populations. HCWs within screening programmes will need to take cognizance of the fact that diagnosing SCD in

newborns or trait in prospective couples does not just involve the passing on of technical medical knowledge, but that the meaning of the information will be interpreted within the socio-cultural context of the couple receiving the information. This brings to the fore the need for the integration of social aspects of genetic screening, counselling and cultural perspectives into the training curricula of genetic counsellors. It would also need to take into consideration appropriate timing for introducing communities to the concept of genetics and its relevance to childbearing and SCD. Ghana does not need to design and implement such a programme right from basics. There are several programmes in the UK the USA that can offer invaluable lessons, albeit that given the particular circumstances of Ghana, it would be unwise to import such programmes wholesale without regard for the socio-cultural context of Ghana.

In the following section, the researcher discusses the social meanings of health, illness and SCD and compares findings to the literature, drawing similarities, contrasts and extensions of existing concepts to findings of the study.

The Social Meanings of Health, Illness and SCD

Social and anthropological scientists (Morgan et al. 1985; Calnan, 1987; Radley, 1993; McGuire and Freund, 1995 and Ahmad, 2000,) have described the variety of lay concepts of health and illness (Herzlich, 1987 and Blaxter, 1990), and the lay discourses that underlie social constructions about the health and illness states. In their studies they report that one lay definition of health as a negative, that is the absence of illness, and another of health as a positive concept coming from within the individual. In this latter

concept, health was conceived of as a 'reserve' determined by 'temperament and constitution' or a state of 'well being'. In yet a further dimension, Blaxter (1983) describes a concept of health as having an element of will-power, self-discipline and self-control.

The categorisation of health

Findings of this study, though comparable with these descriptions, are also distinct in some respects. In her survey, Blaxter described six main categories of health as: not being ill, a functional capacity, physical fitness, leading a healthy life, a psychological concept and a reserve. In this study also, five categories of health definitions were noted as a *sense of wellbeing; ability to exhibit physical strength, resource for economic endeavour; product of healthy lifestyle and clean environment*. These similar categorisations conceive of the concept health as a function of one's 'ability to carry out routine activities', with the 'absence of aches and pains in day-to-day movements' in a 'clean environment'. Furthermore, health as *a sense of well-being* was likened to the feeling of 'goodness' when one can get on with the day's work without any hindrance. This concept of health has been reported by Calnan (1987) to be common among working class women in the UK who perceive health as the 'ability to get through the day' in contrast to their professional counterparts who perceived health as 'being fit'. These findings are in contrast to that of this study, as responses of respondents showed similarities irrespective of high, medium or low levels of income. This may suggest inherent difficulties in attributing social constructions of health according to schema of social classes developed

in the UK, rather than to a people defined by a common culture and a social world within which they cannot exist in isolation (Mishler, 1981).

Health as the *ability to exhibit physical strength* was used in a context of describing the individual's capacity to display physical fitness. Health was perceived as a conservator of strength and the embodiment of physical 'peace' because there is nothing in the body that 'troubles' the individual. This is synonymous with Blaxter's (1983) definition of health as physical fitness and strengthens the popular notion of health as a 'reserve' that diminishes with self-neglect and unhealthy lifestyles such poor environmental health and nutrition.

Health described as a 'key to progress' and as a *resource for economic endeavour* in this study was a new, distinct and different category in comparison to Blaxter's findings and that of other commentators. Health in this study was perceived as an asset for progress that allowed the bearer to go about doing what was conceived of as normal activities such as earning a living and being able to support the family. The importance that men accord to their traditional role as financial resource for the family in this study may explain its distinct prominence in the discourse of the fathers, rather than just a perception of a fluid ability to function: a notion reported by Macfarlane and Kelleher (2002) to be commonly described by older people.

In contrast to the free-at-point-of-use UK health system, the financial burden represented by the fee-for-service health system in Ghana, and the perceived financial burden of caring for a child with SCD in that context, may help explain both the lay construction of health as a resource for economic endeavour, and in turn contribute to the continued stigma associated with SCD in the Ghanaian context. These findings strongly suggest that the social definition of health is influenced by a complex aggregation of peoples' perceptions of their social roles and expectations. It also lends credence to the need for HCWs to critically consider the variety of lay categories of health. Lay knowledge on health needs recognition (Mishler, 1981, Stacey, 1994) in the course of building relationships with families of SCD patients, and in giving direction to the types of education and counselling support to be given.

Since health as a *resource for economic endeavour* is such a strong lay concept, this suggests a congruence of three factors: (1) the Kumasi neonatal screening programme can be considered a success in that it increases the potential for economic contributions from patients with SCD because 95% can survive to 5 years; (2) the fact that economic potential is such a central concept to Ghanaian society suggests that policy initiatives around increasing economic potential would be in tune with popular lay opinion; and (3) from points (1) and (2) it would seem there is an opportunity to persuade health policy makers that investment in neonatal screening and counselling programmes, and treatment of those with SCD, is a good economic investment that accords with popular conceptions of health and popular concerns for economic development, and that therefore SCD programmes could be both effective and politically popular investments.

The Illness State

In this study, the illness state was assessed and findings have shown three categories of lay perception of the illness state. It is described as a source of: distraction; erosion of confidence, and deviance. Illness as a deviance is consistent with the Parsons model of the sick role (Parsons, 1951) in spite of the several criticisms levelled against it as professionally-biased and devoid of lay participation in the illness process (Hornig-Parnass, 1981). Parsons (1951) explains the sick role as following certain codes of conduct. These codes of conduct confer on the sick certain rights and responsibilities. In terms of relating the Parsonian model to SCD as an example of “illness as deviance”, SCD has a multiple effect: it robs families of resources in three ways: (1) by the need to pay extensively for medical care (2) by the fact that whilst in illness states the person with SCD may not be economically active and (3) that even when not in illness state the discrimination and stigma they endure may mean they are unfairly denied access to economic opportunities.

The illness state as a source of erosion of confidence revealed in this study is similar to that portrayed by Sontag (1978) and Radley (1993) as metaphors in the minds of a group. In this instance, the thought that prolonged illness affects the physical presentation of an individual as in SCD (contorted, knotted like sugar cane and smaller in size for age - *woaye ndwendwendwe*) may underlie respondents’ tendency to stigmatise anything perceived as not conforming to the norm. These accounts were linked again to the fathers’ concept of health derived from the cultural and social construction of their reality

of illness and represent a 'truth' seated in the psychological and emotional determinants of health (Morgan et. al.1985; Helman 2000; Freund and McGuire, 1995). These findings represent a body of knowledge with a potential for providing teachers of HCWs in Ghana with the needed foundation on the social context of health and illness. They provide a foundation for rethinking through HCW attitudes to lay knowledge about health and illness and what it has to offer to the process of healing and support care, as suggested by several commentators on health, illness and their narratives (Engel, 1950; Hornig-Parnass, 1981; Stacey, 1994)

Chronic illness in context

Chronic illness is another concept well studied among medical sociologists. It is a disease defined by Rabin & Rabin (1985) through their personal experiences with amyotrophic lateral sclerosis (Lou Gehrig's disease) as '*a social disease in the context of modern medical ideology*'. Several commentators have examined the concept through a wide range of chronic illnesses such as leprosy (Mishler, 1981); rheumatoid arthritis (Bury, 1982); Parkinson's disease (Pinder, 1992); cancer (Mathiesen and Stam, 1995); hypertension (Thorogood, 1990, Morgan, 1996) and diabetes (Helman, 2000; Pierce and Armstrong, 1996; Rajaram, 1997). These experts have come to a conclusion that chronic illness does not conform to the Parson's model of the sick role but rather that it creates a prolonged dependency status of the sick on the significant carer rather than on the medical profession. SCD is a chronic illness, characterised by unpredictable painful episodes of variable length and severity. It has considerable potential for what Goffman (1959) called 'passing', that is presenting oneself in everyday interaction as someone

who does not have such an illness. However, the painful episodes themselves, as well as possible somatic signs such as yellow eyes, recurrent leg ulcers and delayed growth with its associated smaller size for age (contorted, knotted like sugar cane- *woaye ndwendwendwe*) leave the person and their family vulnerable to discovery.

In the accounts of fathers in this study, findings on chronic disease disclosed two categories of meanings: chronicity as *frequent, continual and complex disease* and chronicity as *not related to heredity*. They associated chronicity with an illness that defied cure, was persistent, and had a lingering effect and an eventual potential to kill the sufferer. They confirmed findings in the literature by equating the general concept of chronicity to such common chronic conditions as hypertension, diabetes, cancer, HIV/AIDS, tuberculosis and hepatitis, and felt convinced that such diseases definitely fitted the description of chronicity. However, there were divergent views and reservations about SCD being chronic. Their concept of SCD as a chronic condition reflects an exposure to competing theories of SCD in popular discourse. They tended to distinguish SCD from what they called 'other' diseases such as AIDS, and instead thought of it as in the same category as malaria. The perceived culpable nature of HIV/AIDS and the tendency for the fathers to differentiate it from other chronic diseases (SCD) show the extent to which society is capable of projecting meanings into diseases and drawing markers for each disease condition depending on how it is positioned in the lay community's mind. The degree of culpability accorded different diseases determines their position with respect to stigmatising and labelling as 'social outcast'.

This knowledge suggests the need for remodelling SCD education and training programmes for HCWs and families to include concepts on chronicity and social meanings. Furthermore, in the Ghanaian context, the process of social positioning of the different types of chronic diseases in terms of their respective degrees of social stigma and perceived culpability could be the subject for further research.

Paternal knowledge on SCD

Divergent social perceptions on SCD and its chronic status in Ghana bring discussions to another important aspect of findings in this study: that is knowledge about SCD among fathers. Views among SCD educators and counsellors underscore the role of parent and patient education in SCD management and are said to underpin the success of any comprehensive care programme for SCD (Dennis-Antwi, 2000). This is because educational programmes are largely rooted in encouraging affected persons to comply with care and to positively take control over their lives (Dennis-Antwi, 2000; Okpala et al. 2002). Findings in this study highlight fathers' prior knowledge of SCD before marrying or having their children with SCD. The knowledge about SCD was a mixture of factual medical knowledge blended with experience, myths and lay conceptions. Their statements reflected an incorporation of technical professional knowledge into their lay understanding, and the generation of meanings that may or may not fully accord with technical medical knowledge of SCD. This finding is similar to a critique of the manner in which HCWs interpret screening results on SCD and communicate to families (Dyson, 2005) resulting in ambiguities in presenting laboratory results. It is possible that fathers in this study had been exposed to such interactions with poorly-informed HCWs who impart

a mixed interpretation of haematological findings to them. This has resulted in a call by counsellors of the need for continual education of HCWs involved in SCD care on SCD and thalassaemia (Dennis-Antwi, 2000; Okpala et al. 2002; Dyson, 2005).

Findings on knowledge also drew attention to the use of home remedies for painful episodes. There is evidence to show that the presence of illness in a family leads to attempts to make sense of the illness episode, evaluate particular treatment options available to them and the common adoption of a combination of modern medicine, folk/traditional medicine, supernatural healing rites and religious performances (Nilmanat and Street, 2004). In the Ghanaian socio-cultural context, '*being tied up*' with ropes or strips of cloth at the site of painful joints was described and said to be common in rural communities where the medical concept of SCD is not well grounded and where, therefore, there is reliance on home remedies folk/traditional medicines to relieve pain. This procedure was not considered by the rural communities themselves as punishment, nor by the person with SCD as an abuse of their human rights, but a strategy in the absence of any better available resource to reduce pain and suffering (Nilmanat and Street, 2004). Use of home remedies to meet health needs is common among cultures and may involve a diverse array of what is perceived as workable within the social context of the affected individuals and what is available at the time of onset of illness. These remedies include the use of salt-sugar-solutions and enema for diarrhoeas in rural Zimbabwe, Nicaragua and Saudi Arabia (de Zoysa et al, 1984; Rasheed, 1993; Hudelson, 1993), ayurvedic kinds of medicine for a 'snakebite' or a 'fracture' in Sri Lanka (Wolffers, 1988) and '*ya-tom or ya-mor*' in rural Thailand (Nilmanat and Street, 2004).

Though the use of various types of home remedies was not the focus of this study, the '*being tied up*' concept practiced in Ghana has been reported as a source of concern among HCWs in Ghana due to its associated medical complications arising from poor blood flow through the affected parts thereby resulting in further sickling, poor localised circulation and possibility of bone infection (osteomyelitis) and neuropathy.

These findings suggest that the existing knowledge, as well as home remedies on SCD that fathers have prior to their introduction to the medical model of SCD, is important in understanding the basis for some of the complications that patients may present at SCC for treatment. They also provide lay knowledge that is relevant to the training of HCWs in haemoglobinopathies both in Ghana, and more widely in Africa. Indeed, the use of home remedies for SCD management in rural communities in Ghana presents an interesting phenomenon worth further research.

Knowledge and Diagnosis of SCD

An important issue that has often arisen in SCD diagnosis has been the identification of false negatives or false positives in laboratory testing (Adams, 1994; Embury et al., 1994; Nzewi, 2001) with its direct and indirect cost to families and society. Solubility testing has been noted for non-specificity in diagnosing SCD due to its inability to identify other clinically relevant traits such as AC and A thal and also because of near normal HbA₂ and MCV values (Serjeant, 1992). In this study, there was a reported case of a false-negative in which the test was conducted in London as a means of ensuring specificity and quality but turned out that the woman, who was apparently a thalassaemia trait, was diagnosed as

homozygous haemoglobin A (HB AA). The man was a known sickle cell trait (AS). The result was the birth of their first son with SCD of the $S\beta^0$ thalassaemia type. This finding raises considerable ethical implications. Though the couple could not tell which diagnostic method was used in their case, it shows the level of trust that society places in modern health care and the possibility that, though biomedicine may position itself as a superior form of knowledge to traditional forms, it is not as infallible as this positioning sometimes implies.

Another factor is the screener or investigator and the extent to which interpretation of inaccurate findings could be assigned (Baines, 2005; Dyson, 2005; Mutton and Peacock, 2005). The fallibility of health professionals and the modern diagnostic technologies they use as occurred in this instance need to be acknowledged in the day-to-day interactions with clients whilst recognising and respecting the potential of the lay person to effectively interpret and use medical information towards disease prevention. Training HCW on techniques for sensitive diagnosis for SCD in countries where there are affected populations is crucial in SCD management. In Ghana sensitive testing is sometimes lacking at the district and sub-district levels of health care, resulting in patients undergoing solubility testing rather than more specific ones such as haemoglobin electrophoresis. Advocacy for better services for SCD care should therefore also highlight the application of effective testing mechanisms to exclude false negatives and false positives.

Pre-marital genetic testing and marriage in Ghanaian context

Pre-marital genetic testing is a technology that has been reported to have great success in countries like Cyprus (Angastiniotis, 1992), Israel (Shiloh et al. 1995) and Iran (Ghanei et al. 1997) where governmental initiatives have sought to make the services widely available to promote informed decision-making. Unfortunately this service is not available in most countries in sub-Saharan Africa where a quarter of the population have sickle cell trait, even though the public desire to have the service has been investigated and found to be very high (Durosinmi et al. 1995). The relative acceptability of screening was corroborated in this study where 15 of the 31 fathers who knew about SCD indicated their willingness to test had there been reliable, well publicised and sensitive testing services available at the time of their marriage.

Though these fathers expressed the view that they would not have proceeded with marriage and had children if they knew before hand their trait status and that of their wives, it is worth commenting that decision-making in the choice of partner may be influenced by a multiplicity of social factors and not by sickle cell status alone. Other factors that influenced fathers' decision-making on SCD and marriage included the fact of the birth of a child in courtship. Another factor was a paternal conviction of deliberate lack of disclosure of known sickle cell status by a spouse. These findings underscore the importance and urgency of introducing genetic counselling in pre-marital relationships in Ghana, coupled with comprehensive public education to increase uptake. In the studies in Cyprus, Iran and Israel cited above, it was found that genetic counselling uptake was higher than that of use of prenatal diagnostic services due to the fact that the notion of

aborting foetuses with SCD was incongruent with their religious beliefs. Similar findings were noted in the study of Durosinmi et al. (1995). In Ghana 98% of the population belong to a religious denomination and 82% attend church regularly (Luginaah et al. 2005). The likelihood of high uptake of prenatal diagnosis will consequently be less, suggesting a preference for genetic counselling and pre-marital screening programme, rather than a prenatal diagnosis programme. Moreover, pre-natal diagnosis reported to be successful in some countries like Cyprus (Angastiniotis, 1992) but unsuccessful in others like Iran (Ghanei et al.1997), has been criticised for treating the body of the pregnant woman as an object rather than a part of a human being, for intruding into the emotional being of womanhood and for perceiving the foetus in utero as separate from the mother (Powledge and Fletcher, 1979; Katz Rothman, 1994). All these suggest the need for a culturally-sensitive service in Ghana tailored to the needs of the socio-cultural environment.

Knowledge of SCD and its Meanings to Marriage and Childbirth

This brings the discussion to the related issue of childbearing that has been documented in several Africa based studies as very crucial to the survival of marriages (Ebin, 1982; Cornwall, 2001; Geelhoed et al. 2002; Richards, 2002). Without children, marriages may become destabilized through pressure from relatives to produce children, resulting in fragile intimate relations and severe emotional instability for the women (Ebin, 1982; Ericksen and Brunette, 1996; Cornwall, 2001; Leonard, 2002). Childlessness is perceived as both a personal and a public problem and families go to lengths to use a combination of biomedical, traditional and religious remedies to solve infertility (Olu Pearce, 1999).

Although this study took place in a very different social and economic context than the study of low income African-American women by Hill (1994), her findings were found to be true in this study where respondents expressed their preference for a child with SCD to not having a child at all. To them, childlessness constituted an unacceptable disruption to their biographical trajectory through life: a situation that the researcher, to further develop Bury's notion of biographical disruption (Bury, 1982), calls 'procreative disruption' Indeed, once married, all fathers interviewed claimed that their knowledge of SCD would not prevent them from having children but would instead push reproductive decision-making in the direction of having fewer children so as to meet the cost of caring for a SCD child financially.

Another dimension to the importance of genetic counselling and pre-marital screening in Ghana concerns variable social attitudes to childlessness. There remains a social stigma to the condition of childlessness within marriage in Africa, whereas voluntary childlessness in Western World is regarded as an increasingly accepted choice. However, it is only in recent decades, and then only in higher income groups in the West, that voluntary childlessness has come to be viewed as a lifestyle choice (Gillespie, 1999, Wretmark, 1999). The special affinity to child-bearing in Africa as a cultural demand for women to retain their gender identity has negative implications for pre-natal diagnostic services (Shiloh et al. 2005) and suggests a greater probability of keeping pregnancies as compared to opting for abortions should the foetus be found to have SCD. This strengthens the researcher's argument for genetic counselling and pre-marital screening in Ghana rather than for counselling and pre-natal diagnosis.

Parental knowledge on SCD is crucial for practicing and mastering quality home maintenance skills in SCD management. In this study, findings showed that two-thirds of the fathers (20 out of 31) had gained most of their experience in childcare through observation and experience in dealing with the illness state. Another disturbing revelation was the fact that a majority of the fathers receive minimal or no formal education on their children's condition. Therefore, although their own lay expertise was their primary resource upon which they could draw, this knowledge contained a level of uncertainty, and this helps explain why they sought answers to questions during their interaction with the researcher. These actions further suggest that fathers may prefer a one-on-one interaction as a means to gaining knowledge about SCD. Health education research has shown that in instances where parents are poorly informed about their children's condition, the children's response to care is minimal (Anthony, et al. 2003).

Furthermore, Gallefoss (2004) has shown in the context of patients with chronic obstructive pulmonary disease that patient education decreases dependence on HCWs. This finding can be extrapolated to parents of children with SCD to suggest that parental education on their children's illness will in turn ensure better home care resulting in less hospital visits and hospitalisations for SCD patients. These findings suggest the need for an organised programme of parental education involving both parents and designed in such a way as to offer opportunities for fathers to fully participate, so that their observational and practical experiences could be strengthened with factual medical knowledge.

Lay discourses on SCD

In order to systematically document some of the lay meanings of SCD, many of which the researcher was herself already familiar with, a group of mothers, and a group of specialist health workers were also interviewed as well as the fathers. Findings revealed six main lay discourses on SCD. They were: *A 'bought' disease; the cause of early death; a financial drain; SCD as a social stigma; SCD: a source of despair and the cause of recurrent death.* These lay discourses on SCD tend to categorise patients as people belonging to the phenomenon of social death and results in parents ignoring such children. In such situations, the parents discount these children as non-existent in social terms and wait patiently for the day of their biological death. Parents live in a cycle of fear and uncertainty as to when the 'death' is going to occur to the extent that the best way they could deal with the situation is to psychologically persuade themselves that the child is not one who has come to live but that of one passing through life only briefly.

As a *'bought disease'*, genetic causes are scarcely considered as possible explanation even in the face of a family history of SCD. Genetics is a remote concept and SCD is ascribed and explained as a family curse. This categorisation places it under a spiritual or metaphysical cause where witches and spirit mediums (*juju*) are believed to have purchased the disease and inflicted it upon the family through the birth of the child. By this infliction, the power responsible is supposed to receive a form of satisfaction or gratification for performing that act. Writers on the phenomenon of witchcraft (known as *bayie* in Asante Twi; *aje* in Yoruba) in Africa portray witchcraft as a separate world comprising witches and wizards and evil spirits. Witchcraft remains an important cultural

influence for many Africans, irrespective of religious belief and educational background. Often, a person suffering from the effects of these spirits is unaware of it until s/he starts experiencing problems such as frequent illness as in the case of a SCD child (Ebin, 1982; Barnett et al. 1999; Tremayne, 2001; Richards, 2002). What makes SCD amenable to metaphysical explanations is the fact that a newborn baby with SCD looks very healthy and normal until about five months of age when the disease begins to manifest in the child, requiring frequent hospital attendance and hospitalisations. At that point the normal child ceases to be 'normal'. Reasons must be assigned to the abnormality in the face of the lack of a meaningful diagnosis from the hospital other than fever or malaria. Associated with the frequent ill-health is a change in the physical appearance of the child. Often, s/he loses weight, feeds poorly, is stunted in growth and withdrawn; a state typically described as in this study as '*Woayε ndwedwendwedwe*' (*knotted, small-sized and contorted as sugar-cane*).

These presentations characteristically make a parent very fretful and confused. Without medical knowledge, the only apparently plausible link will be the metaphysical cause. Such a conviction sets in motion attempts to deal with the problem metaphysically thereby leading to visits with spiritualists and traditionalists (Tremayne, 2001; Richards, 2002).

Closely tied to the notion of SCD being a '*bought*' disease is the accompanying possibility of the child being labelled as the cause of the illness itself. This implies that the child is a witch or wizard sent from the spirit world to torment the family and make

them desperate (*source of despair*) with frequent hospital attendance and hospitalisation. In such situations, the child is neglected thereby perpetuating the concept of social death, *recurrent death* and re-incarnation.

Another categorisation of the SCD patients based on these discourses is in relation to Bury's (1982) concept of biographical disruption. This can be explained in three dimensions. First, SCD is a disease associated with frequent ill health and hospitalisations, the child's life is disrupted, interrupted and punctuated with medical care. The daily intake of medications is perceived abnormal when compared with non-SCD children who do not have to live through that. SCD patients become desperate as they grow up and observe the difference in their lifestyle in comparison to their non-SCD colleagues (Ahmad, 2000). This is a situation they must learn through the passing years to accept as part of life, thereby disrupting what should have been a 'normal' passage of life – hence a biographical disruption, and a source of despair both to the patients and families who have to continue caring.

The second dimension is related to the poor and stunted growth and failure to thrive. These commonly result in children who are small comparatively for their age, signifying an interruption in their biographical trajectory of physical growth. The third dimension is, by extension, related to the parents or carers. SCD as a chronic disease justifies a level of dependency of the sick person on the carers. This necessitates the need for carers to make time to meet the health care needs of the patient. In most cases this requires a change of job, reorganisation of routines and appointments leading to disruptions in their lives as

well. These disruptions can by extension of Bury's notion be categorised as social and career disruptions.

Linked to its disruptive nature is the lay notion of SCD as a source of *stigma* to the child and the family as well. SCD can, to an extent, be likened to Parkinson's disease in that its presence in a person raises what is termed as a problem of shame (Nijhof, 1995). SCD assumes a rule-breaking character, resulting in a feeling of shame when in public because through their contorted and knotted appearance patients are perceived as 'abnormal'. A not dissimilar perspective is the social perception of SCD as a condition that sets the affected individual apart from social acceptance because of 'blemish' or 'pollution' from a different physical presentation complicated by a lifestyle of daily medications and restrictions in daily living (Goffman, 1963, cited in Katbamna et al, 2000: 14).

Another concept of relevance here is the loss of identity or self (Charmaz, 1983) upon the birth of a child with SCD. Parents are known to lose their identity and to assume the new social identity of the one 'with that sickly-lanky, contorted and knotted child'. Though Charmaz's concept refers to that of the patient himself, the concept could equally well be applied to the parent who economically, socially and emotionally empathises with the child and gives 'all' in the care of the child (Finch and Groves, 1983). Mothers reported giving up their means of livelihood (a loss of economic self) to care for their SCD children whilst the fathers reported selling their personal effects and putting all their savings into health care bills to keep the child alive, thereby reflecting its lay categorisation as a disease of *financial drain*. Read (2000) argues that mothers do most of the emotional work in mediating the discrimination of society against their children.

Finch and Groves (1983) describe the diverse sacrifices that mothers make in their 'labour of love' to protect their offspring and keep the family from stigmatisation. . This necessitates a renegotiation of their 'self' through the use of coping systems available to them (Bury, 1982; Charmaz, 1983; Hill, 1994; Barbarin, 1999). The evidence from this study suggests that the lay discourses on SCD in Ghana are so powerful and stigmatising, that parents need a strong positive conviction within themselves in order to develop the caring attitude and skills required to look after the child with SCD. In a country of minimal economic resources such as Ghana, public education could go a long way in abating the variety of negative perceptions surrounding the disease and also assist parents in developing the positive self-esteem required to manage a challenging disease such as SCD

In the next and final section of this chapter, the researcher discusses the social aspects of SCD and argues that paternal reactions to SCD are again contextual and influenced by existing knowledge, reactions of significant others, the course of the disease in the child and the availability of coping resources at their disposal.

The Social Impact of SCD on Fathers

Much of the evidence in this study strongly suggest a direct relationship between the level of reaction to diagnosis and individuals' perceived knowledge about the disease, previous practical experience with the disease or what has been said by the lay community, and even in some instances what has been said by qualified health workers. The attitude of nonchalance, of 'not being bothered' described by the researcher is

attributed to the fact that familiarity or non-familiarity with the disease breeds an attitude of '*and so what*' because it either affirms the individual's expectation of the disease being in the family or it just makes no meaning at all since the individual has never had any exposure to the disease. These reactions have been corroborated by findings in Hill's (1994) study of mothers in low-income families.

However, in contrast to her assertion that these reactions to SCD may be related to level of income and experience of racism, the researcher argues that such reactions are more dependent on familiarity or non-familiarity as well as lay perceptions about the disease (Katbamna et al. 2001). This situation brings into focus the need for a strong relationship between HCWs and parents, and public education on SCD as a means to creating better understanding of the disease (Dennis-Antwi et al. 1995; Dennis-Antwi, 2000; Okpala et al. 2002). Public education, which the fathers reported had played an immense role in helping them develop positive attitudes to the care of their SCD children, would go a long way in alleviating or drastically reducing the negative lay attitudes to SCD. Currently, the lay construction of SCD in Ghana is a vicious circle of powerful and destructive lay conceptions of SCD. These are further reinforced by experiences in which, for lack of nationwide neonatal screening and counselling programmes, and lack of affordable treatment, young people with SCD continue to die early, experience repeated painful illness and incur repeated costs of health care, thereby giving the false impression that the lay constructions are somehow natural or inevitable. These negative lay perceptions of SCD are capable of long existence in the collective memory of society if no efforts are made to address them.

A worrying finding, but not one surprising in the Ghanaian context, was that a few fathers directly or indirectly blamed their wives for the diagnosis of SCD in their children by capitalising on the clinical information that their wives were to report at the SCC for confirmatory testing of their babies. Such reactions on the part of fathers has previously been attributed to some of the criticisms made about reproductive genetics, including its tendency towards the promotion of the cultural ideology of motherhood (Hill, 1994), social discrimination of disability (Katbamna et al. 2001) and the social imposition of limits and restraints on the gendered body of the woman as the carrier of the pregnancy (Etorre, 2002). In a case where the newborn screening programme in Ghana is unable to encourage many fathers to come for confirmatory testing, the result is the passing of blame onto mothers. This implies that the newborn screening programme needs to develop an innovative approach to communicating directly with the fathers of newly diagnosed babies about the importance of the diagnosis of SCD and the need for them to be tested, since SCD is genetic and therefore implicates both the father and the mother. It also needs to build into its programme strategies for reducing discrimination against women (Katz Rothman, 1994; Etorre, 2002).

Findings on childcare in this study suggest a degree of paternal dependence on the mothers of the SCD children for their optimal care. This finding is similar to the reliance on women as carers for the disabled among Gujarati Hindu, Punjabi Sikhs, Bangladeshi and Pakistani Muslims living in the UK (Katbamna et al. 2001). This study also found that the type of work fathers do for a living, and a paternal conviction that women

‘should’ be interested in childcare because it is their traditional responsibility to do so, influence the degree of paternal dependence on the mother. However, such dependence, the researcher argues, is traditionally constructed and dictated by gendered roles (Brown, 1996; Oware Gyekye et al. 1996; Salm and Falola, 2002). Fathers felt their moral responsibility was to provide leadership and security to the family by confirming, checking, providing needs and ensuring that the family was doing well whilst the direct hands-on duty to care continued to fall to the woman. Whilst the literature reports across many cultures and societies that caring for children with disability had been the sole responsibility of women, the fathers in this study continued to hold a strong conviction that they are equally meeting their obligations in childcare. They also felt that their seemingly lack of contribution to care does not imply that they do nothing but rather that they are actively engaged in supporting the mothers to carry out their caring duties.

In this study the parents felt committed to the involvement of SCD children in household activities in order to help their children to gradually develop a sense of responsibility and chart a course towards independence. Such actions are also reported to improve sibling relationships and to remove a feeling of preferential treatment for SCD children (Midence and Elander, 1994).

Also important was parental ability to develop a strong positive bond between them and their children as a way of supporting them in their struggle to gain normality. A crucial part of growing up among SCD patients is the engagement of a process of building independence and negotiating own identities to gain ‘normality’ in an environment in

which they are perceived 'abnormal' (Stuart 1996; Atkin and Ahmad. 2001). It is also a period characterised by rejection of constant overprotection resulting in mental confusion, uncertainty and fear among parents as they are unsure of limits of control whilst trying to reconcile this with the advice of sickle cell counsellors to treat the children as near normal as possible whilst nonetheless observing for complications (Hill, 1994).

This implies that if counsellors were provided with practical medical advice modules as part of their continuing professional education, then this in turn could enhance competency-building among parents to confront such situations and deal with difficult questions asked by children. Modules on developing independence among children, especially towards their adult life, are crucial in the Ghanaian context where government service support systems are virtually non-existent compared to their counterparts in UK and USA, where SCD and disability service advocates have ensured improved services (Oliver, 1996; Atkin et al. 2000).

The existing US literature on the response of unmarried biological fathers to their SCD children and their mothers was that of indifference, denial and blame (Hill, 1994). This is, however, incongruent with findings in this study where Ghanaian unmarried (that is, unmarried to the biological mother) fathers expressed feelings of distress and powerlessness due to their inability to regularly see their children to carry out their expected gender roles. This feeling reflects a sense of caring and duty to their children.

This was found to be a contributory factor or an underlying reason for continual discord between parents who are separated in marriage but have children with SCD in this study.

Some of the fathers claimed that mothers used care for SCD children as a focus for dispute, in that any delay by the fathers in meeting financial obligations was met with insults or threats. The researcher therefore argues that much as it is possible for a parent to position himself or herself to the outside world as a good parent, it is possible that the widely reported but little observed phenomenon of paternal neglect of SCD children stems from strong marital conflicts between the two parents rather than the birth of an SCD child per se, with the SCD patient becoming an unfortunate victim caught between the two feuding parents (Eddy and Walker, 1999). Strained marital relationships raise serious implications for care of children with chronic conditions. This therefore implies that though SCD in itself may not be the reason for discord and marital separation, it is, following a divorce or separation for other reasons, a subject that becomes the site of potential disagreements between the parents. Indeed, in this study, four of the fathers were divorced from the mothers of the SCD children.

According to Boateng (1996), the breakdown of marriages has partly contributed to the emergence of recent increase in single parenthood in Ghana. He further states that single-parent families headed by women, form about three-quarters of the total of such families and are perceived as more vulnerable families because of low-income levels among women in Ghana (Salm and Falola, 2002). Findings also showed that all the divorced mothers except one had remarried, thereby, potentially at least, reducing their financial

vulnerability. The existing literature however suggests that reconstituting marriage is only one way of achieving security of care, and not necessarily the most effective, as UK evidence suggests that money in households is unequally distributed, with the man controlling finances, and monies not necessarily getting to the woman or child (Pahl, 1989). One could therefore argue that what is required is an entitlement to monies for all child-rearers/carers.

In the UK, this has resulted in the institution of a national child benefit system where a welfare payment is paid directly to all main carers of children, usually, but not always, the mother. This implies that though women may remarry in the Ghanaian context to enhance financial security and childcare, the monies do not necessarily end up with the woman. The man may still control monies and release them voluntarily or under duress. This is obviously worrying and especially important in the case of the SCD child where much money is required for regular treatments and mothers, who might well not press the men for contact and money if they had healthy children, may then feel compelled to press the father for money because of the financial pressures of SCD in a fee-payment health system like Ghana.

With respect to the context of the Ghanaian health care system where self-financing continues to be the main available option, it is important that sustainable financial support systems are explored and institutionalised for families with SCD children who cannot afford care. Such a system will need a combination of conventional loan schemes and traditionally acceptable means of recouping monies borrowed. Another strategy is to

ensure that families with SCD children all enrol into medical insurance schemes being introduced for all Ghanaians to cover all the cost of care. This scheme is currently in its infancy. Out of a total of 127 registered schemes, 107 have been operationalized. However registered members continue to be limited to a few people. Efforts are being made to include and expand coverage (Ghana Health Insurance Council-GHIC, 2006)

In assessing the fathers' social and emotional reactions to SCD, the researcher felt that the fathers held feelings of fear, uncertainty, frustration, and pain upon the birth of an SCD child. However, these reactions were not always explicitly expressed, being tempered with culturally constructed remarks that 'A man does not cry.' Nevertheless, despite the attempts to hide their grief, two fathers did cry during their interview with the researcher. The existing literature on parental reaction to chronic illness indicates a vast array of emotions such as frustration, guilt, anxiety, helplessness, loneliness, isolation and resentment (Midence and Elander, 1994; Hill, 1994; Anionwu and Atkin, 2001). The researcher suggests that though the literature may report such reactions to chronic illness, the expression of such reactions are culturally determined and strongly influenced by gender as exhibited by the fathers in this study. Therefore it is possible not to overtly detect extreme emotional reactions to chronic illness among populations in places such as Africa where culture regulates the expression of pain, anger and frustration by gender and where such expressions are more likely to be culturally available to women.

Again, findings showed that SCD-related grief is associated with the bitter experiences of complications, rather than the child per se. Problems related to the financial burden of

the disease, frequent hospitalisation, fear of sudden death and anxiety about short life span were reportedly the basis for the grief. Also included in the basis for their grief were experiences with painful crisis and the notion of the child suffering through no fault of his own. Nine fathers had strong feelings about the impact of SCD on affected families and expressed this by recounting their experiences with the financial burden of SCD and how it had resulted in their inability to acquire property or any longstanding legacy for their children. They claimed that they had been unable to acquire property because all their savings went into meeting health care costs for their SCD child. Moreover, in looking into the future, they needed to plan for that child's adulthood by saving to build a lump sum that could serve as insurance for the child's care since employability may become an issue in the future.

Hill (1994) notes that stress due to SCD among low-income African Americans is often related to lack of or minimal information about how to care for the SCD patient. Chamba and Ahmad (2000) support this assertion in their study of language, communication and information needs of parents with severely disabled children in the UK. By contrast, however, fathers in this study located their stress on issues directly linked to their locus of control such as inability to ensure, confirm and monitor care. This is probably because they did not perceive themselves as direct carers but rather responsible traditionally for monitoring care and meeting financial costs. It could therefore be said that source of stress in SCD care is directly related to ones perceived role in childcare. This suggests that support programmes aimed at enhancing parental competencies in childcare need to

initiate education from these parental perspectives whilst encouraging shared responsibility and renegotiation of roles where necessary.

Fathers' description of experiences with SCD show a close linkage with the variety of lay discourses about SCD described in this study, in that they shared the wider social construction of SCD as an unwanted, unacceptable and stigmatizing disease in society. This situation calls for a re-designing of programmes aimed at supporting families in living positively with SCD. Programmes will need to adopt strategies that will break the cycle of pain and bitterness that parents experience. Without that, SCD will continue to be stigmatised, and parents will not be able to openly discuss their children's conditions, nor argue for the provision of better care. Currently, most families have little or no organised support from the Ghanaian Government (Dennis-Antwi, 1997). Without efforts to break the stigmatising effect of SCD on patients and carers, such lack of involvement by government will continue, with the vicious cycle of people with SCD being thought of as dependent victims. Such victim-blaming needs to be curtailed by persuading the government to take responsibility for providing for the disabled. Again there are important lessons in the UK and USA that Ghanaian advocates could adapt for the particular socio-cultural setting of Ghana. Such lessons include the adaptation and adoption of health policies that ensure quality, comprehensive and free healthcare (Anionwu, 2001) for all disabled persons and the provision of social policies that provide financial relief or 'soft loan' schemes for poor families affected by debilitating chronic diseases.

Another important policy concern is that of employment. It is critical to direct and promote education, competencies and skills development to improve the employability of the SCD patient. This policy is important in underpinning independence among disabled persons such as those with SCD (Franklin and Atkin, 1986; Twigg and Atkin, 1994; Oliver, 1996; Atkin et al. 2000). The enactment of such policies in Ghana and the translation of these policies into simple evidenced-based interventions will culminate in breaking or drastically reducing the sickle cycle of pain, fear, frustration and financial difficulties affecting families. It will also contribute to breaking the negative cycle of lay discourses and ultimately help to de-stigmatise SCD.

This study also revealed that whilst fathers showed good intentions and were effectively doing a good service to their children by carrying out some of the roles traditionally assigned to women, they saw such actions as evidence of their exceptional efforts, with little regard for what Western feminists would conceive of as failing to take their share of direct care and restricting the women's social potential. For example, the fathers claimed they felt more capable of accessing better health care than their wives or partners. Bhakta et al. (2000) explain similar findings in a study and link them to gender differences in different communities where men have greater experience of fulfilling such responsibilities. However, this finding is at odds with the social achievements of single women who have made remarkable contributions to the advancement of society and in the care of their disabled children (Oliver, 1983 cited in Finch and Groves, 1983; Hill, 1994). It is important that programmes geared at increasing paternal involvement in health care for SCD patients aim at harnessing the concept of men more as equal partners

in the direct care of the children. This is a challenging programme indeed, for it necessitates a rethinking of a deep-rooted traditional division of labour.

Another finding of this study was related to relationships with HCWs. Findings showed that HCWs assumed expert positions in most discourses, thereby giving little opportunity for the fathers to share their feelings and their thoughts about their children's condition. In essence the fathers felt powerless in decision-making about their children (Atkin et al. 2000). This was reported to cause feelings of inferiority among the fathers. Although fathers felt they could more readily speak up and challenge HCWs, and therefore that they could get a better service out of the health professionals than could their wives, they could equally well develop a strong aversion to the health care setting. This was because if they took the initiative and attended health settings and tried to be proactive in questioning care, or in seeking more information than had been provided, they ran the risk of being rebuffed by the HCWs and therefore having their self-image as 'men-in-control' undermined. Since in their view the woman was more used to having to accept the hospital instructions unquestioningly, the fathers felt that the mother was therefore more psychologically suited to having to accept a paternalistic service. Indeed, they perceived that HCWs, especially the doctors, did not respect them as parents. Studies in the UK on relationships of HCWs with families of disabled children have shown that carers felt supported when HCWs were kind, considerate or sympathetic towards them. They would describe a service as good depending on the attitudes of the HCWs towards them (Bhakta, 2000; Chamba and Ahmad, 2000) whilst continuing dominance by HCWs was perceived as inhibitive in promoting parental control (Oliver, 1996).

The power and control exercised by HCWs has been criticised by Oliver as resulting from the governmental structures designed to provide care to clients. The findings in these studies may explain the attitudes of HCWs reported in this study and the perceptions by the fathers and calls for a change of attitudes of HCWs to carers that allows some parental control and responsibility over decision-making. Of course, this will neither be easy nor quick to achieve.

Since SCD is a life-long disease, medical professionals and family members will need to work as a team in its management (Okpala et al. 2002), and it is essential that national SCD programmes inculcate team building as an integral part of management. It also calls for a re-think as to who is the central part of this team; the patient, carer or HCW. Stacey (1988) argues that the patient and the main lay carer, who though often, may not always be the mother, should be central to the team. In practice, however, they are often not even conceptualised as part of the team by the HCWs.

Whilst this suggestion may be laudable, it is a challenge in a country with a very high doctor-to-patient ratio ranging around 1: 10,000 in urban areas and 1: 14,000 in rural areas (partnershipvolunteers.org/Ghana,2005). This calls for the adoption of the concept of skill-mix in Ghana where other non-medical professions could be allowed to increasingly provide care. In current practice, certain cadre of nurses (Medical Assistants, Midwives and Community Health Nurses) in Ghana are allowed to offer basic health care services in communities and clinics as part of the primary health care strategy. The level

of acceptability of this concept at all levels of health care in Ghana is contentious though, given a situation where doctors occupy most of the leadership positions.

Numerous authors have indicated that medicine creates and maintains itself as a profession in order to secure control over the terms and conditions of its work (Freidson, 1970; Johnson, 1972) and that the relationship of nursing as a profession relatively subordinated to medicine is a condition of the success of that strategy of professionalisation (Davies, 1995). The resistance of doctors to accept large-scale skill-mix solutions to the problem of scarcity of human resource can arguably be attributed to their attempts to retain control over all technical aspects of health care, thereby perpetuating their position as the leaders of the health care system. This has resulted in a situation of automatic respect and popular support for doctors by the public, as they are perceived as that cadre of HCWs capable of health care provision and healing.

Whilst the concept of skill-mix could be further explored, adoption of approaches such as parent-to-parent education, peer education in partnership with HCW, using accredited parents as peer educators, could be ways of taking burden off the shoulders of HCW in parent education. Role modelling is also another possible approach in patient and parent interactions as a means to promoting positive living and a desire to achieve among patients.

Katz Rothman (1994) has noted that where reproductive decision-making centres on pre-natal diagnosis, the mother is positioned as responsible for bearing less-than-perfect 'needful' children: a situation she believes robs families of the ability to accept such

children as they are. In such cases, families are pushed in the direction of controlling the 'quality' of children born to them.

Findings in this Ghanaian study, however, suggest that information about sickle cell directs parents to limit the total number of children born, rather than to abort those with SCD. The researcher argues that fathers do not seek to regulate the quality of the children they bear as in the case of pre-natal diagnosis, but rather that their focus is in having fewer children in order to maximise their limited resources for better care of the SCD child. It is possible that fathers have assumed such positions due to the absence of pre-natal diagnostic services in Ghana and that, should such services become available, the Ghanaian faced with reproductive decision-making on a 'poor-quality' foetus may make different decisions. In this respect, it is worth noting that abortion is common among single unmarried young Ghanaian women (Daily Graphic, 2006). On a further note however, in a country where religiosity is highly regarded, it is not certain how receptive pre-natal diagnostic services would be to couples in Ghana. This is an area that may require further research.

The financial cost of sickle cell disease management has emerged in this study as a powerful influence militating against optimal care of SCD patients by families, and in this sense both represents the greatest burden on families and is the source of disagreement among parents with SCD children, especially those who are separated or divorced. This situation calls for the adoption of supportive strategies that enhance parental ability towards financial management. Parents could be facilitated to contribute

to small savings schemes, known locally as '*susu*' schemes, where they could put by small amounts of money on daily basis to accrue into a substantial amount for emergency needs. The Sickle Cell Foundation of Ghana, new body set up to manage SCD-related ventures could champion this effort as a national initiative. The success of this initiative has the potential of bringing substantial relief to affected families.

Governmental responsibility in SCD management and support should, however, not be overlooked, even in the face of active non-governmental initiatives. The recent introduction of the national health insurance scheme in Ghana by the incumbent government presents hope for better clinical care of patients. It is important that SCD as a health issue is comprehensively catered for in the basic insurance packages.

In a world characterised by fear, anxiety, frustration and pain in caring for their SCD children (Frydenberg, 1997), findings revealed that fathers harnessed multiple coping resources such as social support, embracing the medical concept of SCD, seeking for financial loans and use of self esteem (a feeling of 'I can handle this myself') in dealing with stress arising from SCD. Other strategies included religion, positive framing of self and child, optimistic thoughts, sustaining good relationships and monitoring the mastery displayed by the mother. Findings on social support, embracing the medical concept of SCD, religion, positive framing of self and child and optimistic thoughts are corroborated by many of the studies on SCD and other chronic illness (Jessop, et al. 1988; Hill, 1994; Midence and Elander, 1994; Anionwu and Atkin, 2001). Coping resources documented in this study to be harnessed by fathers include tapping into social family support available

to them such as getting siblings, grandparents and cousins involved in daily care. Further strategies involved seeking financial loans to meet cost of care and the ‘monitoring’ of the mastery of their wives in home maintenance skills in SCD.

Whilst in Hill’s study achieving mastery was reported as a coping mechanism among low-income African American mothers of SCD children, this study found that fathers did not seek to directly master care of their children, but rather sought to fall back on what they knew best to do: that is checking, confirming and ensuring that their wives had given care to the children. Thus they were adept at monitoring the mastery of their wives and used that as a coping mechanism in responding to SCD stress.

Religion also featured strongly as a coping mechanism used by the fathers. According to the literature, religion is perceived as a great source of comfort and strength when one is confronted with the challenges of life. It is reported to give meaning to hardships, suffering and tragedy as well as a great pillar to lean on for courage and hope (Henley and Scott, 1999). For some religious persons, the power of God is what sustains them and helps them to move on in life despite very trying situations. Certain critics have described this reliance on God and religion as fatalism. Fatalism is reported as not allowing the affected population to act and seek for answers to their situation. The fatalistic attitude is believed to limit the sphere of control of the affected families and does not create the desired opportunity for them to pursue a collective drive to change institutional and social policies that negatively affect them. Other commentators on religion and health have indicated a clear activist/fatalist dichotomy as being influenced by peoples’ social classes.

In such accounts those in the middle class are more likely to choose an activist stance compared to those in the lower class who assume a fatalist position (RUHBC, 1989). Others argue that the position of fatalism is not total or passive and that individuals are continually involved in cooperating with God to improve health (Mullen, 1994).

The researcher argues that the concept of fatalism is not well supported from the evidence of her research because in the case of this study, fathers reported that they were actively participating through their support groups in lobbying Government agencies and collaborators for the provision of better services. They actively supported the idea of universal education to all Ghanaians on SCD using both mass media and interpersonal approaches. They expressed the need for a bigger centre of excellence for the study and management of SCD in Kumasi and a scheme of financial support for affected and needy families to access to mitigate the cost of care. This showed that the fathers were not just resigned to fate, but were continually and actively harnessing available resources within their limits to address the challenges that beset them. Though they may have wished to be able to do more, they would remain hampered until the Ghanaian government recognises SCD as a disease of public health importance.

Furthermore, the term fatalism is discriminatory and presents people as totally out of control of their challenges. However, humans are dynamic beings created to actively adapt and mould their ever changing situations to meet their needs. It can generally be said then that the variable coping strategies used by fathers are resources for positive living that could be adopted and taught to families living with SCD so that they would be

able to choose appropriate coping strategies that suit their particular socio-cultural circumstances. Religiosity as a coping mechanism therefore should not be discouraged in the Ghanaian socio-cultural context.

CHAPTER EIGHT:

CONCLUSIONS AND RECOMMENDATIONS

In the course of this thesis, the researcher has presented an in-depth description of the reported reactions of fathers to having a child with SCD. Although SCD is a debilitating genetic disorder of the red blood cells, affecting several millions of people in sub-Saharan Africa, and is the commonest genetic condition of epidemiological importance to Black Africans, it is scarcely regarded as a disease of public health importance in Africa itself.

Though there is literature that describes the physical, emotional and socio-cultural implications of SCD within the UK and US context, there is minimal information on the African, and in particular the Ghanaian, situation. Parents, especially mothers, were reported to experience a good deal of psychological and emotional frustrations in providing care for their SCD children, but there were gaps in the literature concerning the experience of fathers of children with SCD. Moreover, the researcher's own experiences in observing the social environment within which families affected by SCD have lived over the years in Ghana, and the seemingly limited involvement of fathers in the care of children with SCD, generated her interest in investigating the meaning of SCD to fathers and the extent to which they were affected by the disease in their day-to-day interactions.

The researcher therefore sought:

- To investigate and describe the social and cultural meanings of sickle cell to Ghanaian fathers of children with sickle cell disease (SCD).
- To understand and describe the feelings, motives and behaviour of Ghanaian fathers of children with SCD.

The researcher, using a modified ethnographic framework, conducted in-depth tape-recorded interviews with thirty fathers of SCD children and moderated focus groups with nine mothers with SCD children, and with seven specialist health workers on the subject of investigation.

In this final chapter, the researcher outlines the conclusions that can be derived from the study and suggests recommendations for health and social policy development in Ghana. In doing so, the study takes into consideration the socio-cultural context of bearing a SCD child in Ghana, the challenges of parenting a SCD child as a father and the need to tailor training of specialist health workers in genetic counselling, pre-marital testing and SCD care to the socio-cultural context within which patients and families make meaning of the illness situation.

This concluding chapter is set out in three sections. The first section draws conclusions on each theoretical construct derived from the study and described previously in Chapters 4-6, and tries to draw wider inferences from these findings. The second section covers recommendations for health and social policies respectively. In the final section, the researcher describes the original contributions this study has made to the existing

knowledge on SCD and argues for further areas of research into aspects of health, policy decision-making and the social positioning of screening services for the haemoglobinopathies, both in Ghana and across sub-Saharan Africa as a whole.

Conclusions to the Study: Traditional Contexts, Social Meanings and Impact

This section outlines the major conclusions to be derived from the study of fathers of children with SCD. It is set out into three sections namely: 1) Traditional Courtship, Marriage, Children and Family Division of Labour 2) The Social Meanings of Health, Illness and SCD and 3) The Social Impact of SCD on Fathers.

Traditional Courtship, Marriage, Children and Family Division of Labour

The first contextual feature of the Ghanaian experience of SCD concerns the impact of the four stages of marriage, the social framework of childbearing and the gendered roles in the division of labour, and the impact these have on SCD.

Courtship, marriage, childcare and SCD

There are four series of steps to marriage between the Ghanaian young man and woman. The first two stages are described as courtship and knocking, whilst the third and fourth are traditional marriage and marriage of ordinance. Evidence from the study attests to the fact that the two former stages are commonly associated with sexual activity termed as *Mpena twe* - stealing access to the woman without the consent of parents, with a resultant pregnancy and the possible birth of an SCD child. Although it is not argued that SCD in itself *causes* tensions between the couple, any birth of a child with SCD can then become the focus of any disagreements between the woman and the man, as they negotiate their

lives through the four stages of marriage and onset of parenthood. With the father distancing himself to avoid further disagreements, his knowledge of the technical aspects of SCD is impoverished to the extent he is not involved in parental education, neither formally through the SCD clinic nor informally through everyday involvement in the care of the child.

In cases where SCD children were born in marriage fathers reported checking, confirming, ensuring, advising, instilling moral discipline and inculcating appropriate respect for God as their gendered contribution to child care. This also involved setting controls towards protection from ill-health by ensuring that they avoided triggers to illness such as '*bad play*' (boisterous playing, playing outdoors in cold weather without wearing protective clothing). Men only exceed this monitoring role in special cases where the woman is for some reason unable to meet her share of the division of labour, and in such cases men would then negotiate a more extensive contribution for themselves, in order to ensure that family dynamics remained in equilibrium.

Children with SCD can be further disadvantaged by becoming the focus of any parental tensions. The relative stability of relationships around children will depend on very broad social trends. However, this does suggest a role for community genetic education and family planning in order that, whether inside or outside of formal marriage, that children with SCD are born into circumstances where parents are receptive to the technical education about what SCD really entails, and are aware of the support needs of an SCD child.

The symbolic value of children and SCD

Respondents in this study report children as invaluable gifts of God for every marriage. Children are perceived as a 'must have' in every African marriage and couples would do everything within their limits to bear children. Efforts to ensure having a child include drawing upon a combination of modern medicine, folk/traditional medicine, supernatural healing rites and religious performances.

As such, respondents report their determination, once married, to bear children irrespective of their sickle cell status. This indicated that knowledge of trait status in marriage would not necessarily translate into voluntary childlessness, a concept which is gradually becoming acceptable among single middle class women in Western societies. Rather, couples with trait status report an outlook on reproductive decision-making that limits the number of births rather than embraces childlessness. This represents a strategy of maximising the couple's financial and emotional ability to care for any children already born with SCD, rather than a decision to prevent the recurrence of another child with SCD.

This finding suggests that in Ghana, there may be a willingness to take up pre-marital genetic counselling and testing as well as family planning services. This would be different from Western models of antenatal screening, which arguably focus on prenatal diagnosis to determine the 'quality' of the already conceived foetus in utero. This is because with an established cultural affinity for children (a symbol of virility, honour and social respect and recognition of parenthood) and high religiosity in most parts of Africa,

abortion of a so-called ‘affected’ foetus would not be well regarded. Rather a premarital education and testing programme could help dissuade uncertain couples from having children, and help prepare couples who are confident in their long-term relationship for the eventualities of a child with SCD.

The Social Meanings of Health, Illness and SCD

The second contextual feature of the Ghanaian experience of SCD concerns the lay meanings of health and illness in general, and lay conceptions of SCD in particular, and how these frame and influence the social experience of having a child with SCD.

The lay concept of health

Fathers report that childbearing brings to the couple a sense of responsibility that is defined traditionally by gender, with a cultural expectation that the couple will bear children socially perceived as ‘normal’ and without blemish. The ideal cultural notion of healthy babies underlies much of the expectations of couples in childbearing as it directs their aspiration for a strong, healthy and normal baby to nurture into adulthood.

In this study the fathers’ understanding of the concept of health is directly related to its physical, social and economic benefits of a ‘healthy’ child. . The fathers value health as a resource that enables them to meet family obligations. They also perceive that their individual health is crucial to their ability to meet the health care needs of their children with SCD: a condition they have come to experience as a highly financially-laden disease and for which no financial support system exists. These self-concepts mean that a child

with SCD is perceived not only as a challenge to the father's own capacity to meet family obligations, but that a child with SCD may not realize the ideals of health and economic achievement for subsequent generations.

The lay concept of illness and chronicity

Fathers describe SCD as an illness state in three ways: *distraction, erosion of confidence and deviance*. SCD is deemed a distracter and a destroyer in that it takes the affected person away from routine activities. SCD is further perceived as eroding confidence, in that the perceived ability to achieve economic independence is erased and the individual moves from an independent to a dependent status. In turn, this alleged dependency status casts the father and the person with SCD as deviants in that they are said not to be able to fulfil roles of providing for the needs of the household.

All thirty-one of the fathers compared SCD to commonly known illnesses such as hypertension, diabetes, cancer, AIDS, tuberculosis or malaria. However, the fathers situated SCD in relation to the existing pantheon of chronic diseases in two different ways. First, although twenty-three fathers agreed with the proposition that SCD is chronic, this attribution seemed to derive from their exposure to technical medical knowledge, rather than a personal conviction through experience. Since HIV/AIDS is a known blood-related and chronic illness, and since SCD on the social scale of stigmatisation is more acceptable and bearable than HIV/AIDS, this made it difficult for fathers to embrace the notion that SCD was a chronic condition, and as such they persisted in their conviction that SCD is not a serious disease like HIV/AIDS.

The second, and minority perception, is that SCD is more comparable to common and endemic conditions such as malaria: a comparison that brings out the perceived culpable nature of HIV/AIDS and the non-culpable aspect of SCD where the affected person cannot be directly blamed for having the disease.

Most often the positioning is determined by a synthesis of social experiences, factual medical knowledge and lay conceptions. Furthermore, respondents' perception of SCD draws attention to the fact that genetics was found to be a complex and alien concept that does not exist in the Ghanaian social construction of disease causation. Rather, repeated occurrence of a disease in families is attributable to physical disposition to disease or spiritual causes.

These findings raise implications for making recommendations for health and social policy in Ghana, and to the extent that comparable situations exist throughout sub-Saharan African, for other African countries as well. Health care workers would need to understand how parents construct their sense of what SCD is from a combination of lay sources, their partial apprehension of technical medical knowledge, and from using other diseases to mark out a specific understanding of what SCD is. The importance of both health and children as economic resources suggests that newborn screening programmes, including clinical care and education for SCD patients, enabling the survival of such children to become economically active in the future could serve both needs of government and, to the extent that this will help break the cycle of stigma of children with SCD themselves.

Paternal knowledge of SCD

Although about half of the fathers interviewed in this study have some prior knowledge of SCD before marrying or having their children with SCD, their accounts reflect an incorporation of technical professional knowledge into their lay understanding, itself a blend of experience, myths and lay conceptions. This is illustrated in their variable use of two local terminologies '*ahotutuo*' and '*sasaboro*', terms used in describing painful crises experienced by patients. Often, the fathers use '*ahotutuo*' to explain their understanding of SCD whilst some fathers differentiate the two by employing the category of age to qualify '*ahotutuo*' as occurring in younger people and recurring throughout life, whilst '*sasaboro*' starts in older people and is related more to arthritis or rheumatism than SCD.

In the absence of conventional medical knowledge on SCD, and the absence too of accessible health care in certain communities, fathers report a reliance on local approaches in pain management. The notion that someone with SCD '*has to be tied up*' describes efforts by carers to relieve SCD patients of the intense pain associated with the painful episode. Tying up provides transient numbness and dulling of the pain and bears some resemblance to acupuncture as an alternative source of treatment.

In this study, there was a relative acceptability of the concept of pre-marital counselling and testing. Fifteen out of the thirty fathers who knew about SCD indicated a willingness to test in the presence of reliable, well-publicised and sensitive testing services at the time

of their marriage. Moreover, this study confirms high levels of religiosity; valuing of children, and a dislike of abortion in marriage. Together these suggest a relative acceptance of premarital counselling and testing alongside a relative rejection of prenatal diagnosis and selective termination.

Two-thirds (20 out of 31) of fathers interviewed reported that they received no direct formal technical education on SCD, and that any knowledge was gleaned indirectly from observing the care executed by the mother, or by trial-and-error. It could be argued that in African countries paternalistic attitudes to traditional division of labour has kept men on the fringes of day-to-day childcare. However with the changing trends in culture, difficulty in accessing reliable domestic help from the extended family system, globalisation and modernisation, there is a window of opportunity for increasing paternal involvement in childcare, through subtle inclusive strategies.

Lay discourses on SCD

Fathers in this study report six main discourses on SCD. The discourses are: *SCD as a 'bought' disease; the cause of early death; a financial drain; SCD as a social stigma; a source of despair and the cause of recurrent death.* These findings are indicative of extensive popular negative reactions to SCD. This creates a considerable challenge, since it is by comprehensive care of the person with SCD that they can become a living demonstration of the potential of people with SCD, and yet the very possibility of such investment is undermined by the negativity of the prevailing discourses.

The Social Impact of SCD on Fathers

This third section describes the reaction of fathers given the Ghanaian context. It includes the reaction of fathers to an SCD diagnosis; their care of the SCD child; the reactions and coping strategies adopted by fathers; and their reported relationships with HCWs.

Reactions to Diagnosis

The reactions to SCD exhibited by fathers in this study are a product of the socio-cultural context. Fathers typically describe feelings of nonchalance, extreme worry, shock, uneasiness, sadness, discouragement, devastation, frustration, despair, apprehension, depression, withdrawal, pity and empathy for their SCD children, and a presumption that their children will have shorter life spans. Moreover, fathers show a pattern of individualised process of grieving around the diagnosis of SCD. The resolution to their feelings commonly means a decision to accept the child as a gift from God and to care for the child within their best capability.

In a few instances fathers directly or indirectly blamed their wives for the birth of the SCD children. This arises out of procedural gaps in the process of communicating results of screening and request for confirmatory testing of parents thereby resulting in situations of known trait status of mothers whilst the status of fathers remain largely unknown. This perpetuates victim-blaming and abuse of mothers as the alleged cause of every abnormality in children.

Extending care to the SCD Child

Findings suggest a degree of paternal dependence on the mothers for the optimal care of their SCD children. Fathers in the study claim lack of time due to work as a main setback to their optimal involvement in childcare. Their responses also show a conviction that there are appropriate gendered roles in childcare. Therefore they as fathers 'should' not be deeply involved, but rather actively engage themselves in supportive capacities. The fathers may report a feeling of moral responsibility towards renegotiating roles in times of crisis, but the reality remains that women shoulder the work of hands-on caring.

These call for some modifications in the training of HCWs to include strategies on supporting couples in child care, and in learning how they can encourage active participation of the SCD child in family life and in family chores, so that all the family develops a mind-set in which the child with SCD is more than a transient member of the family.

Level of parental education on SCD and social reactions

Paternal social reactions to SCD have been shown in this study to be influenced by the degree of continual education received at the SCC and the support group meetings held monthly in Kumasi. The fathers report that parental education on SCD plays an immense role in enabling them to re-frame SCD in a more positive light than allowed by prevailing negative lay discourses.

Paternal Coping Responses to SCD

Findings reveal the fathers' ability to harness a multiplicity of coping resources such as social support, embracing the medical concept of SCD, money (seeking for loans) and self esteem (a feeling of I can handle this myself) in dealing with stress arising from SCD. Other responses include religious belief, positive framing of self and child, optimistic thoughts, sustaining good relationships and monitoring mastery. These variable responses represent resources for positive living that could be adopted and taught to families living with SCD.

Seeking financial support to mitigate the cost of care as a coping response raises implications for holistic care of SCD patients. It calls for the institution of diverse sources of funding for chronic conditions. Such sources should include and strengthen access to health care through the newly introduced health insurance scheme in Ghana. Other sources such as community-based loan schemes set up and managed by civil society rather than government organisations could also be explored and resourced to ease the burden of caring for SCD children.

Fathers express positive aspects of their children beyond the horizon of frustration and coping responses. They describe their children as people with character, affection, desires and dreams that must be nurtured. The current state of SCD management requires such a positive outlook as a tool for teaching parents on positive framing and reflection in developing the potential of SCD children to live independent lives.

HCWs, parent and patient relationships in SCD care

Fathers sometimes felt that through relationships with HCWs their position as heads of their household was sometimes undermined. This situation often arises when fathers are in disagreement with the course of treatment, are not permitted to know about the condition or where they are of the opinion that their children are not receiving the best of care. Fathers report medical mismanagement as common right from diagnosis of SCD to care on admission. National SCD programmes therefore need to inculcate team building with the patient and parents as central and integral to holistic management. This suggestion however raises two main dilemmas for consideration.

The first dilemma is concerned with the current high doctor-to-patient ratio in most African countries. In Ghana, this ranges from around 1:10,000 in urban areas to 1: 14,000 in rural areas. The second dilemma is related to skill-mix in health care delivery in Ghana and a perceived resistance of doctors to accept skill-mix solutions to the problem. Since the problem of the brain-drain continues to affect the human resource base of the Ghanaian health sector, strategies for mitigating the challenges associated with such scarce human resource are necessary. Adoption of approaches that promote peer education among parents, patients and families such as parent-to-parent education and peer education in partnership with HCW could be ways of taking the burden off the shoulders of HCW in health education. For such a strategy to be successful HCWs will need to cautiously select, train and accredit parents as peer educators.

Role modelling is another possible approach that could be adopted as a means to promoting a desire to achieve among patients and parents. Client-centred strategies to HCW-patient interactions will also need inclusion into the training curriculum of HCWs to improve on the relationship in optimal care of patients and families.

Based on the conclusions of this study, the researcher outlines the following recommendations for implementing SCD programmes in Ghana.

Recommendations for Health and Social Policy in Ghana

There is currently a low level of health and support services provided for patients and families affected by SCD, whether in Ghana specifically, or in Africa more generally, due to the poor per capita income of most African countries and the limited resources available for allocation to the many pressing priorities of most governments. Findings of this study have pointed out the financial pressures facing families with a child with SCD, the social implications of care especially on fathers within a system of limited public education on SCD, prevailing negative lay discourses on SCD, challenging experiences with care of the SCD child, and limited specialised health and social support services confined to a few cities and towns, with the remaining patients receiving care in general outpatient departments scattered across district hospitals. The recommendations that follow arguably also have implications for other developing countries affected by SCD, especially those in sub-Saharan Africa.

*Health Policy and Strategies for Improved SCD Management in Ghana**Advocacy for public health recognition of SCD*

Despite its high prevalence in West Africa, SCD is currently not recognized as a disease of public health importance. Moreover, development of services for SCD takes place in a context of extremely high patient-doctor ratios; a drain to the developing world of medical, nursing and allied health professional staff; and a reluctance of doctors to accept measures such as large scale skill-mix in staffing health programmes. As elsewhere, the medical profession maintains itself as the profession in charge of all health programmes in Ghana thereby securing and controlling the terms and conditions of its work, and pushing other equally skilled non-medical health personnel to the background.

The researcher recommends that a strong advocacy group comprising all interested bodies currently working for the cause of SCD in Ghana be formed to create sustained political awareness about the impact of the disease in Ghana and what can be done to ensure improved services. This can only be achieved in conjunction with local advocacy strategies in which positive achievements of children and adults with SCD are reported so that, in turn, parents will be more able to openly discuss their children's conditions, and argue for the provision of better care.

Identifying and accessing human and material resources

The process of institutionalizing a policy on SCD programme nationally in Ghana has a very credible and living example in the NSSCD project based around Kumasi. The use of existing service structures and available human resource can be cost effective and

facilitative of the process. This is because SCD-related activities could be integrated into the routines of the existing services through the training, redeployment and re-location of key personnel into the SCD specialist programme.

Providing standardized clinical services

Evidence from the screening programme in Kumasi has so far yielded very positive results that provide a basis for advocating for universal screening of all babies born in Ghana for SCD. The screening programme as at December 2004 had diagnosed 3,354 (2%) out of a total of 177,283 newborns with SCD, and enrolled 2,366 of them in the clinic; 5% (109) of those 2,366 were known to have died. The remaining 2,265 represent [95% of the 2,366 babies with SCD enrolled] young babies who have been helped to survive to school age (Ohene-Frempong, 2005). This represents 2,265 parents who have been saved from grieving due to loss of child, and 2,265 potential future contributors to the Ghanaian economy (Dennis-Antwi et al, 2005). The researcher therefore suggests that the cost of screening be included in the basic package of any health insurance scheme approved in Ghana, a measure whose costs could be off-set by economic as well as health and humanitarian gains from newborn screening

Skills development of HCWs

An important dimension to health care for SCD patients is the extent to which health care workers in Ghana are trained to care for SCD patients and their families. It is recommended, that SCD be the subject of more formal continuing professional education for HCWs, in addition to basic information on SCD during their professional training as students. This continuing professional education should not be confined to clinical

aspects of care, but needs to prepare HCWs in social aspects of care too. This could include not assuming superiority over parents (such that the parents feel out-of-control of their ability to negotiate better care or question the care being given to their children); and developing an understanding of some of the social issues impacting on the SCD experience in Ghana, such as lay discourses, stigma, the gendered division of labour, and the relation of the different stages of marriage to attitudes to child-rearing.

Patient and public education programme on SCD

Parental knowledge on SCD is crucial for practicing and mastering quality home maintenance skills in SCD management. The evidence from this study has attested to the tremendous benefit that parents have accrued from the continual education sessions run at the SCC as part of the NSSCD project coupled with that of the regional support group meetings scheduled monthly in Kumasi.

Respondents attested to the significant role that continual parental education had played in assisting them clarify the myriad of lay and stigmatizing discourses on SCD in Ghana, develop the caring attitude, confidence and skills required to care for their children with SCD, as well as offering a supportive environment for developing social and emotional stability in seeking an improved quality of life for their children. Based on these findings, the researcher recommends the institution of a national policy on public and parental education on SCD as part of the comprehensive national SCD policy and in collaboration with governmental and non-governmental agencies in Ghana.

Furthermore, fathers in this study stated that meeting one-on-one gave them the opportunity to ask questions in a non-threatening manner and facilitated their understanding of the need to increasingly and actively participate in the care of their SCD children. They therefore requested more of such sessions to improve on the existing knowledge about the disease and care. The researcher therefore recommends interactive education sessions as a one of the key channels for developing the concept of 'Men-As-Partners' (MAP) in SCD care.

MAP is a concept born out of the need of the public health community to develop creative strategies to reach men in the face of growing worldwide concerns on reproductive health issues (Wegner et al. 1998; Peacock and Botha, 2004; Engenderhealth, 2005). With findings of this study showing men as monitors of women's mastery in SCD, and a seemingly latent participation in care highly influenced by traditional gender roles, the researcher proposes the design of a culturally sensitive MAP programme for increasing men's active participation in SCD care. Strategies for involving men could include education services for fathers through seminars, conferences, chats, discussions and workplace interactions all coupled with messages and materials that project the benefit of men's involvement in health care for the SCD child. Fathers could also be brought more to the fore in discussing health issues affecting the family through using women, with their consent, as the gatekeepers to men. For instance, letters could be addressed to fathers as well as mothers, inviting them directly to come for confirmatory testing of SCD screening, rather than simply expecting the mothers to convey this information.

Other new methods emerging out of this study as recommendations are peer-to-peer education by parents and role modelling by successful patients. For the strategy of outpatient education at SCC, modular education programmes for parents/patients on relevant topics such as health maintenance procedures, fever and infections in SCD, nutrition, pain management at home, palpating the spleen at home, inheritance of SCD are proposed. Other equally important topics that have emerged from this study and which have not been previously considered in most of the education sessions with patients in Ghana include stages of marriage and their relevance to childbearing in SCD, lay discourses on SCD and their effect on care, traditional gender roles and the importance of re-modelling for better SCD care, lay concepts of health, illness and chronicity in SCD, social reactions to SCD and possible coping mechanisms for dealing with complications, factors influencing paternal extension to care and strategies for addressing them.

Inseparable to the provision of health care policy is a wider social policy that addresses the social needs of patients. The lack of such a broader policy would itself result in poor maximization of health benefits and low quality of health. In the final part of recommendations towards policy, the researcher therefore proposes aspects of a social policy relevant to the Ghanaian context of SCD programming.

Social Support Services

Major pillars of an overall social policy on SCD include, health care, social and financial security, employment, education, and social support systems, and these are addressed in turn in this section of recommendations.

Health Care

This study has thrown up three areas for the improvement of health provision for children with SCD. These include improvements in clinical care, which itself could contribute to dispelling ideas of the inevitability of delayed, twisted and contorted growth and early deaths from SCD. Second is the new-born screening programme (including relatively inexpensive prophylactic treatment and parental education of care of the child with SCD), which has already shown its effectiveness in drastically reducing childhood deaths associated with SCD. Third is the possibility of premarital screening, a screening programme that may influence decisions to proceed through all four stages of the Ghanaian marriage process and/or the desired family size, rather than the Western notion of prenatal diagnosis and selective termination. In the case of the premarital screening, faith-based organizations, such as the Christian churches have been shown to have a potential role in enrolling couples to such programmes.

Social and Financial Security for SCD care

The financial cost of sickle cell disease management, coupled with the associated lay notion of SCD as a 'bought' disease, has emerged in this study as a powerful tool militating against optimal care of SCD patients by families. These negative perceptions

draw attention to the urgent need for a system of financial provision for SCD care that promotes family cohesion and financial commitment to caring for the affected child.

The health care system in Ghana has for a long time been built on a fee-for-service system whereby clients pay for services rendered - a major financial burden on households (McIntyre et al. 2006; Piette et al. 2006). Furthermore, the World Bank has recognised that out-of-pocket payments for health care are capable of making a difference between a 'poor' or 'not poor' household (Claeson et al. 2001). Moreover, recent international recognition of the burden of user fees instituted through the health sector reforms initiatives of the 1980s and 1990s (Gilson, 1998) has culminated in mounting pressure on such countries to introduce alternative approaches to health care financing; the most popular of which has been the health insurance schemes.

In 2003 therefore, the Ghana Government passed the National Health Insurance Act 650 (GoG-NHIA, 2003) to meet this international requirement thereby bringing into law the establishment of various mutual health insurance schemes (NHIS) at the community, district, regional and national levels to facilitate the financial accessibility to health care.

As at January 2006, 107 out of 127 registered schemes had become operational. Each scheme has a mandate to operate a basic minimum package that allows beneficiaries to access basic care at contracted health care facilities (GHIC, 2006). Currently it is not very clear what minimum package SCD patients enjoy, and the extent to which they are covered for complications of the disease such as organ problems and their related surgical interventions. As the first element of a strategy to underpin social and financial security

for SCD care in Ghana, there is therefore scope for the Sickle Cell Association of Ghana (SCAG) and the Sickle Cell Foundation of Ghana (SCFOG) to negotiate with the Ghanaian Government National Health Insurance Scheme to maximise this cover.

A second element of a financial strategy would be to support existing community-based savings and credit schemes that abound in Ghana, such as local savings scheme called '*susu*' (Bartle, 1996; Pankhurst, 2002) where families themselves could informally contribute and support each other as an informal system of credit scheme.

A third element is the training or retraining of the unemployed patients or parents in income-generating activities to equip them with the skills to venture into self-sustaining economic initiatives to help them mitigate the cost of care. Again the SCAG and SCFOG could spear-head strategies aimed at accessing support from local and international organisations such as the Opportunities Industrialisation Centre (OIC) or the National Board for Small Scale Industries (Steel & Webster, 1992; Attahir & Saffu, 2005).

Employment

Another important aspect of social policy for SCD is that of employment. It is a critical measure to direct and promote education, competencies and skills development and the employability of the SCD patient. This policy is important in enabling independence among disabled persons such as those with SCD. This is because employment is an important factor that defines a person's identity and determines individual ability to

access material needs, the lack of which precipitate emotional and psychological distress (Anionwu and Atkin, 2001).

On the Ghanaian front, several calls have been made on the need for the government to enact a national policy on disability and employment. A disability bill submitted to parliament in 2004 is still pending thus perpetuating disquiet and marginalisation (Ghanaian Chronicle, 2005). This disability bill represents an opportunity for the social groups representing SCD in Ghana to lobby parliament in order to create a legal framework within which to work to improve employment prospects for those living with SCD.

Basic Formal Education

With over 12,130 primary schools, 5,450 junior secondary schools and 503 senior secondary schools (Ghana Home Page, 2006), Ghana's Education Sector presents as a critical sector with the opportunity for reaching a formidable group of young people with basic information on SCD. Early exposure of Ghanaian youth to SCD education will go a long way in promoting public informed decision about genetic testing and counselling, choice of partners, marriage, inheritance of SCD and SCD care in Ghana.

Such opportunities could enhance pupils' understanding of SCD as a chronic condition and why affected patients exhibit school absenteeism, sudden illness, poor participation in extra curricular activities, and appear of small stature with a yellowing of the eyes (Ohene-Frempong & Dennis-Antwi, 1998). Besides, teachers' knowledge on SCD promotes positive relationship with the SCD patients and establishes a sense of

responsibility to ensure the welfare of the child during peer associations. Evidence from the NSSCD project in Ghana and others in the UK have shown that teachers have limited or no knowledge on SCD thereby resulting in some hostilities towards patients in schools such as refusal to use toilet facilities frequently or exemptions from extra-curricular activities (Atkin, Ahmad & Anionwu, 2000; Dennis-Antwi, 1997). Introduction of SCD education into schools could reduce such incidences and transform teachers' attitudes positively. The researcher therefore recommends the inclusion of a policy provision for integrating SCD education into the curricula of basic schools. Such inclusion can be made through dialogue with the Curriculum Development Division of the Ghana Education Service. The SCAG and SCFOG could facilitate this activity to a successful outcome.

Social Support Systems

Evidence from available literature attests to the immense role that social support systems play in reducing stress associated with SCD care, with social workers playing facilitative roles in accessing social support for patients (Anionwu and Atkin, 2001). Unfortunately the situation has been different in Ghana, in that social support for patients has been limited to the hospital situation, and even then to instances where patients can afford to pay for care.

In the Ghanaian context of SCD care, the role of social support in the present day management of the patient cannot be overemphasised. Social support workers are critically needed to support the parents of children with SCD in accessing optimal care, providing vital information, assessing needs, guidance and counselling as well as the

provision of recreational, social and cultural experiences. It is not uncommon to find that many SCD patients are poorly educated, unemployed and therefore unable to afford their care. There is the need for a system of social support in place to address the emotional, psychological and in some cases the health care cost of patients. To date, there are only four social support groups belonging to the SCAG and positioned to lobby for improved services for SCD patients in Ghana. These have been set up in the cities of Accra, Tema, Kumasi and Sunyani and are grossly inadequate to meet the needs of patients nationwide.

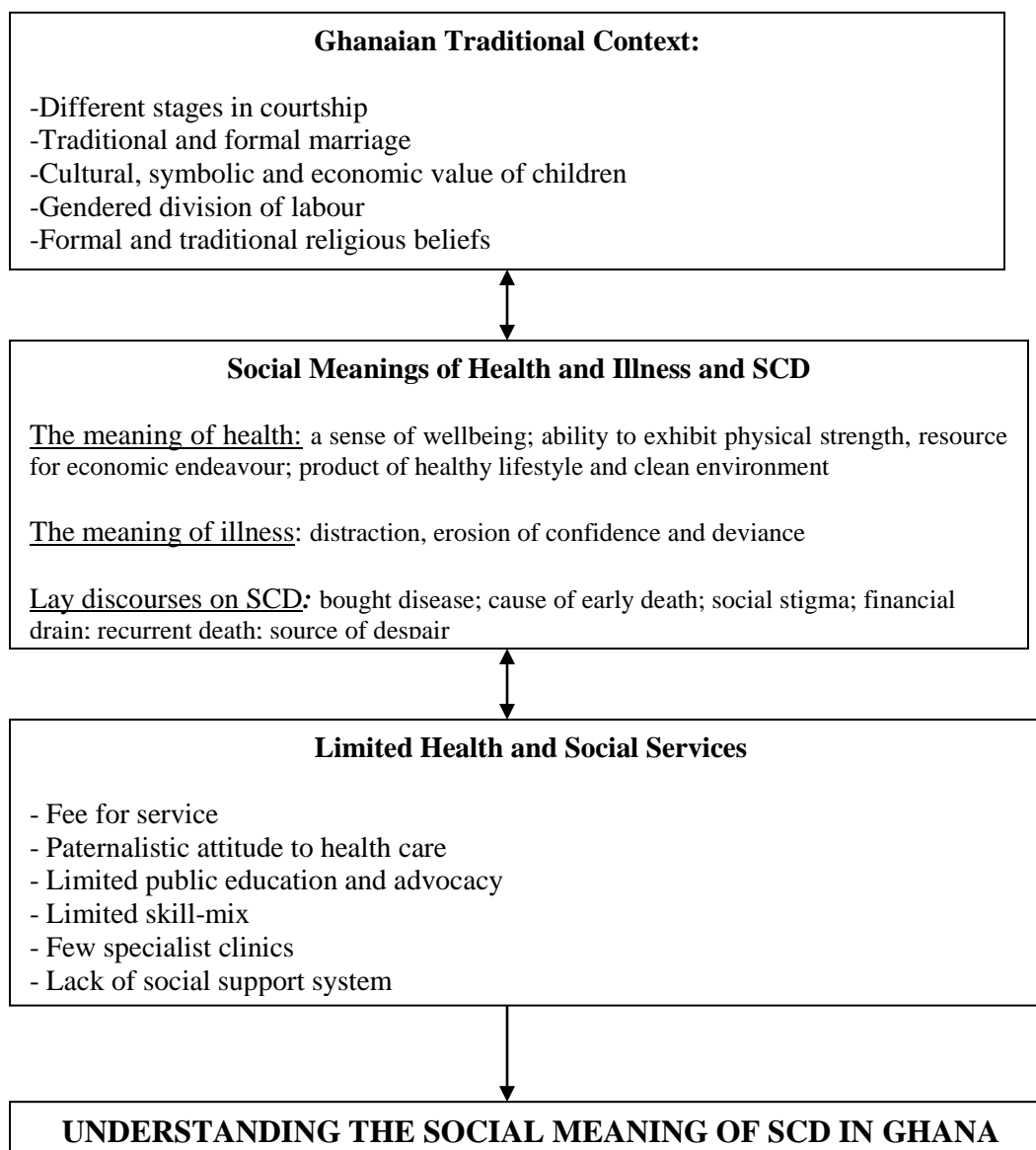
In this concluding part, therefore, the researcher recommends as part of a social policy, the attachment of a social worker to SCCs in Ghana and the setting up of at least one social support group in every region. These workers could help build social networks, and provide fellowship and social support to patients and families to complement efforts of the health facilities. The role of the support worker could also be to act as a catalyst to better and improved services. In the final section of this chapter, the researcher addresses a number of original contributions to knowledge emerging out of the findings of this study and suggests areas for further research into SCD in Ghana and sub-Saharan Africa as a whole.

Original Contributions to Knowledge and Areas for Further Research

The researcher's original contribution to the knowledge consists of demonstrating that we can only understand SCD in Ghana by an approach that considers all the socio-cultural influences on SCD. These influences include the different stages of courtship, traditional and formal marriage, the cultural symbolic and economic value placed on children, gendered

traditional division of labour and the power of religious beliefs (Christian and African traditional religion) existing among individuals and families. Other influences were related to the social meanings of health and illness, lay discourses on chronic illness, the extent of health service provision in Ghana, its paternalistic nature (limited partnership with patients and families); coupled with the limited skill-mix which compromises the availability of specialist personnel to manage SCD. These influences can be illustrated using a simple diagram as presented in Figure Seven below:

Figure Seven: Factors Influencing the Understanding of SCD in Ghana



The derivation of the above flowchart has been based on the analysis of findings using the method of a modified ethnographic approach in which the researcher listened to fathers' perspectives in their own framework through the conduct of in-depth relatively unstructured interviews. Moreover, the interpretation of words were dependent on relating their perspectives to all the underlying features of the Ghanaian society, culture, health service provision and the interactions of these factors in such a way as to understanding how those perceptions and experiences were structures by wider influences.

Furthermore, the thesis breaks new ground in describing, in an integrated way for the first time, the meaning of chronic illness (SCD) to fathers, and the social aspects of living and caring for such children. It provides a vivid description of paternal care for SCD children and the diversity of proactive, innovative, reactive, responsive and decision-making skills fathers employ in their day-to-day encounter with SCD within an African socio-cultural context. Within this overall context, there are four main contributions to knowledge generated by this research namely:

- 1) Documenting the Ghanaian socio-cultural context of courtship, marriage and birth, and its influence on SCD: The four stages of marriage (courtship, knocking rites, legal marriage and traditional marriage) have each been described. It has been suggested that the nature of any complications in the subsequent relationship derives from the stage of this four-fold process the couple have reached, and that this in turn may affect whether or

not, and the extent to which, their child's SCD becomes a focus for their disagreements. This study suggests that in particular the unexpected birth of an SCD child during the stage of courtship or knocking rites can be the source of legitimacy that the father may seek to distance himself from an unwanted relationship. This in turn may undermine the effective care of the child by both parents as the eventual separation in the relationship results in continual discord and dispute between parents with the child being a focal point for their enmity.

2) Providing a description of the social meaning of health to fathers as a 'resource for economic endeavour' that enables them to earn a living to meet their gendered roles as the breadwinners of the family. The centrality of economic potential to the lay concept of health means that SCD is perceived as a double challenge: it is thought to destroy the future economic potential of the young person, but through the financial costs of treatment to also undermine the father economically in the present. On the other hand, the manner in which the chronic nature of SCD is taken up within the lay discourse is that the symbolic positioning of SCD in relation to blame and social accountability for illness is subject to reconstruction through comparisons with diseases like malaria (with similar signs and symptoms to SCD infection) and emerging blood related diseases like HIV/AIDS. This study is significant also in documenting all the lay discourses on SCD in the Ghanaian context. These six lay discourses include: *SCD as a 'bought' disease; the cause of early death; a financial drain; SCD as a social stigma; a source of despair and the cause of recurrent death.*

As a ‘bought’ disease, SCD is purchased spiritually by the enemy to undermine the economic advancement of the affected family. As a cause of early death and a financial drain, SCD by frequent ill health and hospitalisations commonly and continually drains the family of all their financial reserves whilst at the same time truncating the life of the affected child earlier than anticipated. SCD is perceived as the cause of recurrent death and a social stigma in view of parental experience of birth, early death and repeated rebirth of SCD children over time. The social construction of such experiences, coupled with frequent hospitalisation and the different physical appearance of the child when compared to the norm, results in stigmatisation and possible alienation of the child. Generally, the culmination of various SCD-related experiences is desperation in the face of continual parental pressure to ensure survival.

3) Establishing the nature of fathers’ involvement in health and childcare: The existing literature reports that children with disability have tended to be the sole responsibility of women, influenced also by notions of obligation, responsibility and normative expectations. This study shows fathers exhibiting a strong perception of being equally and actively engaged in childcare in the background. However, this self-perception of equal care-giving is seen through the lens of traditional gender roles, and these roles themselves greatly influence these paternal perceptions of childcare. Thus the fathers’ role consists more in *monitoring* the mothers’ more hands-on care-giving, and in stepping in to fill any essential vacuum in care-giving, rather than in any real concept of greater equality in domestic roles, at least as it would be understood in the contemporary Western world.

4) Describing the social impact of a child with SCD on fathers in Ghana: The existing literature on parental reaction to chronic illness largely describes the vast array of maternal emotions. In this study fathers recount a wide range of reactions to the birth of a child with SCD including feelings of nonchalance, fear, uneasiness, sadness, discouragement, apprehension, depression or withdrawal and a presumption that their children would not live long upon the birth of an SCD child. These feelings appear to derive from society's perceived knowledge about the disease and their own previous practical experience with the disease. However there are strong attempts to mask these feelings in accordance with culturally determined gender expectations that a 'man does not cry' thereby perpetuating the popular image that the mother is the one severely affected. In addressing these reactions, fathers exhibit patterns of coping responses including seeking financial loans, use of a mindset of 'I can handle this myself', an emphasis on sustaining good relationships with the employer, and monitoring the mastery in care-giving displayed by their wives.

Areas for Further Research

The results of this study also suggest some fruitful areas for future research on SCD in Ghana. First, in a country where religiosity is highly regarded, it is not certain how acceptable pre-natal diagnostic services would be to couples in Ghana, and this could be explored in further research.

Second, in the Ghanaian context, the process of social positioning of the different types of chronic diseases in terms of their respective degrees of social stigma and perceived culpability could be the subject for further research.

Thirdly, although the use of various types of home remedies was not the focus of this study, the practice, especially in the more rural villages, of ‘*being tied up*’ has been reported as a source of concern among HCWs in Ghana due to its associated medical complications. These findings suggest that the existing knowledge as well as home remedies on SCD that fathers have prior to their introduction to the medical model of SCD is important in understanding the basis for some of the complications that patients may present at SCCs for treatment. An understanding of these lay practices, and the medical complications they may engender, is relevant to the training of HCWs in haemoglobinopathies in Ghana. Indeed, the use of home remedies for SCD management in rural communities in Ghana itself represents an interesting phenomenon worth further research.

Conclusions

This chapter has focused largely on drawing conclusions and making recommendations for health and social policy on findings related to the three main constructs emanating from the analysis of findings into the study of the social meanings of a child with SCD: the reaction of, and the social impact on fathers in Ghana. The three main constructs discussed have been 1) the traditional context of Ghanaian courtship, marriage, children

and family division of labour, 2) the social meanings of health, illness and SCD and 3) the social impact of SCD on fathers.

The major conclusions drawn from the study are that there are a number of socio-cultural factors in the Ghanaian tradition of courtship, marriage, child-rearing and household division of labour that influence the experiences facing fathers in relating to a child with SCD. However, the fathers appear amenable to a programme of genetic counselling and testing, provided this is focused on premarital screening and counselling, respects the highly valued nature of children in Ghanaian society, and helps families make decisions about family size where they have a child with SCD, rather than aim to prevent the birth of children with SCD per se.

Fathers perceived health as a resource for economic endeavour. By contrast SCD was a distracter from life's routine, a robber of one's confidence and a destroyer of health and thereby financial security. Repeated occurrence of a disease in families is attributable to physical disposition to disease or spiritual causes, and not to genetics or heredity.

There are several lay discourses surrounding the birth of a child with SCD. SCD generates a series of reactions in fathers' of affected children. Notable among them are the feelings of nonchalance, extreme worry, shock, uneasiness, sadness, discouragement, devastation, frustration, empathy for their SCD children in pain and a presumption that their children have shorter life spans. These expressions are generally a product of the socio-cultural context within which the fathers find themselves, perceived knowledge

about the disease, lay discourses, HCW reactions as well as the course of the disease in the child. Moreover, fathers draw upon a multiplicity of coping resources such as social support, embracing the medical concept of SCD, money (seeking for loans) and self esteem (a feeling of I can handle this myself) in dealing with stress arising from SCD. Other responses include religious belief, positive framing of self and child, optimistic thoughts, sustaining good relationships and monitoring mastery of wives in SCD home care.

These conclusions have led to a number of recommendations for health and social policy in Ghana as a means to re-programme SCD management. Suggestions for health policy have included the setting up of a national advocacy group to lobby for improved and quality care for SCD patients nationwide. Also recommended are strategies for setting up national specialist sickle cell centres at national, regional, district and community levels as a means to increase accessibility to better health care.

Identification, training and re-training of health care workers using a curriculum that takes into consideration the socio-cultural aspects of the meaning of SCD and its psychological impact have been recommended. Also suggested are universal newborn screening, patient and parent education programming with an orientation towards integrating men-as-partners in care. These important considerations are paramount to the development of a standardised and quality care services for SCD management in Ghana.

As part of social policy, the researcher recommends the establishment of genetic counselling and testing programme set up within the SCFOG as a mechanism for promoting public interest in knowing their sickle cell status to facilitate reproductive decision-making. At the same time, financial support systems through the national health insurance scheme and community-based savings and loans schemes, employment facilities, introduction of SCD into basic curricula of Ghanaian schools and social support services are outlined for critical inclusion into a social policy aimed at providing the necessary empowerment towards enhanced well-being and better access to care.

Finally, this study has made original contributions to the literature on the social aspects of SCD management. The thesis discovers and provides an integrated description of the meaning of chronic illness (SCD) to fathers, and the social aspects of living and caring for such children. It is clear that helping fathers, as well as mothers in their endeavours, could in turn have substantial benefits for the well-being of people living with SCD Ghana.

On the whole, these analysed findings with a focus on the discrete area of SCD and generated through a modified ethnographic study of thirty-one fathers, mothers and HCWs have shown that researchers and HCWs cannot continue to perceive and explain SCD only within a medical gaze but rather through an inclusion of the social experiences of SCD in Ghana. This thesis theoretically represents an affirmation of the relevance and importance of sociology and social policy for holistically understanding health issues. It

also increases the potential, relevance and efficacy of social interventions to improve the experience of living with SCD in Ghana.

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APPENDICES

- I Topic Guide with Twi Translations**
- II Information Sheet about the Study**
- III Ethical Application**
- IV Consent Form**
- V Field Diary**
- VI Example of Documenting the Process of Analysis**

Appendix I Topic Guide for Fathers with Twi Translations

Note: The 'Asante Twi' translated versions have been inserted under each question in italics

Study Title: *The Social Meanings of a Child with Sickle Cell Disease: The reaction of, and the Social-Psychological Impact on Fathers*

- A. *Explain about research using information sheet (translated in twi)*
- B. *Explain consent form (translated in twi)*
- C. *Get a voice recorded consent*

Socio-demographic Details

Name & Address (will not be recorded on to tape)

Wo din ene baabi a wote anaa wo ye adwuma

Tel Number if any (will not be recorded on to tape)

Wo ahoma torofo ye sen

Age

Wo adi sen?

Number of Children

Wo wɔmma sen?

Marital Status : (Single, married, separated, divorced, widowed)

Wo wɔyere anaa?

Number of Wives

Wo wɔyerenom sen?

Religion

Edeen na wo som?

Occupation

Adwuma ben na wo ye?

Where your parents live

W'awofo ete he?

Observations by researcher if interview is held in house

Nεa mpεsenpenen mu ni no huu ye εwɔ agya no fie.

Living with children

ɔne ne mma na ete anaa?

Own a car

ɔwɔ teaseenam anaa?

Type of housing

Edan ben na te mu?

Surroundings

Ne mpɔtem te sen?

Questions

Courtship and Marriage

1. Tell me about how you and your wife met got married/had a child (Probe for knocking rites).

Ekwan ben so na wo ne wohokafoɔ hyiae na mo ware ye?

2. Describe your feelings generally about marriage and childbirth before you had children. Has this changed?

Sen na w'adwene ete fa awareε ene awoɔ ho ansa na mohye ase awo? Saa adwene yi asesa anaa?

Symbolic Value of Children in Marriage

3. Describe your feelings when you learnt that your wife was pregnant with your first child?

Sen na eyεε woɔ emere a wo Obaa no εka kyere wo se ɔyem w'abakan no?

4. Were the 2 of you married then? Explain. If unmarried, what did you do when the pregnancy occurred?

Saa embere no na m'oware anaa? Se na monware ye a, edeen na wo yeε ye emere a yinsen no baa ye no?

5. How did you feel when it was born? What did having that child mean to?

Sen na eyee wo ɔ emere a woyere no ewoo ye no? Awo no na wo te asee sen ?

Role of father in Childcare and Division of Labour

6. Describe your role in household activities. For example the varieties of activities you are involved in when you return from work. What do you do at home over the weekends?

*Edeen na woye wo ɔ efie ansa na woak ɔ adwuma? Wo pɔn adwuma ba fie nsoe?
Memeneda ne Kwasiada nsoe?*

7. What role did you play in bringing up your first child?

Emere a wo ewoo w'abakan no edeen na naa wo ye fa ne ntete ye mu?

8. What role do you play in bringing up your other children?

Se efa womma no nyinaa entete ye mu no edeen na wo ye fa ho?

9. Describe your typical day with your children.

Yen fa no se homeda bi a w'ank ɔ baabiara no edeen na wo ne mmofra no ye da mu no nyinaa?

Knowledge and Lay Meaning of SCD

10. Tell me about what you knew about sickle cell disease (SCD) before you 2 got married.

Na wonim biibi fa ahotutuo yaree SCD ho ansa na wo ne wohokafo ɔ eware anaa mo ehyia?

11. Tell me what you knew about SCD before you two had your child with SCD.

Na wonim biibi fa ahotutuo yaree SCD ho ansa na wo ne wohokafo ɔ mo ba a ɔwo yare yi bi no?

12. Would your previous knowledge about SCD have made any difference in your decision to marry? Explain.

Sε anka na wo wɔ nimdee efa SCD ahotutuo yareε ho dada a, ekwan ben so na anka ebeboa wo ama w'asi w'adwene pi efa w'awareε ho?

13. Would your previous knowledge about SCD have made any difference in your decision to have a child? Explain.

Sε anka na wo wɔ nimdee efa SCD ahotutuo yareε ho dada a, ekwan ben so na anka ebeboa wo ama w'asi w'adwene pi efa SCD ahotutuo yareε eba woɔ ho?

14. Tell me all that you know now about SCD (definition, signs and symptoms, treatment and home maintenance).

Ka nea wonim efa ahotutuo yareε ho kyere me.

15. In what way have you been helped to know or learn more about SCD to enable you better care for your child with SCD? Explain (family, friends, health workers social groups etc.)

Ekwan ben so na w'atumi enya nimdee efa yareε yi ho na etumi aboa wo ama w'atumi ahwe w'akodaa yi yie? Saa mmoa yi efiri he? (eye abusua, nnamfo, apommuden asoeye, akuokuo anaa asɔre)?

16. Tell me the story about the day you were first told your child had SCD (what happened).

Ka dea esi ye emerε a ye kyere wo sε wo ba no wɔ ahotutuo yareε yi be no?

17. Describe how you felt? Why did you feel so? What were your thoughts?

Ebaa saa no edeen na wo ho yεε woɔ? Edeen nti na wo ho yεε wo saa? Edeen na na ekɔso wɔ w'adwene mu?

18. Tell me the story of what you and your wife did about the news. What decision did you make and why?

Edeen na wo ne wohokafoɔ eyεε ye? Mo sii m'oadwene sen? Edeen ntira?

SCD: A Social Stigma

19. Did you tell anyone else about the diagnosis? (denial, secrecy, stigma) Who and why that person?

Ebaa saa no, obi wɔ hɔ a mokakyere no anaa? Hwan? Edeen nti na mo ka kyere saa nipa yi?

20. How many children do you have with SCD?

Mma sen na wo wɔ a wommo wɔ SCD yaree yi bi?

21. Is that child a first born, second, third, last? Does it matter which position s/he is?

Explain.

Saa ba no ɔ to so sen? So se ɔ ye abakan anaa ɔ to so mmienu anaa mmiensa no eye biibi a eha wo anaa?

22. May I know if they're all alive? (If any dead, Probe for what happened leading to the death. Why does he think the child died?)

Wɔ n nyinaa te ase anaa?

Religious and Social Beliefs and Implications for Paternal Care

23. What is your understanding of health? Illness?

Wo te apomodɛn ne yaree ase sen?

24. Tell me what you understand by chronic illness. Is SCD one? Explain?

Wo te yaree koankro ase sen?

25. What does it mean to have a child with SCD as a man in this culture and as a father?

Wɔ mo amammerɛ mu no sɛ wo ye agya a n' abofra wɔ SCD ahotutuo yaree bi a na aseɛ ne sen?

26. Tell me the social conceptions you have heard about SCD. Why do they say that?

Edeen na w'atete sɛ amanfo ɔ eka fa SCD ahotutuo yaree yi ho ? Edeen nti na wɔmmo ka saa?

27. Why does the society give such meanings to a child with SCD?

Wogyedi sɛ edeen nti na ɛma nkronfo ɔ susu saa ɛfa mmofra a wɔmmo wɔ SCD yaree yi ho?

28. Has these social meanings been responsible for the way you feel right now as a father of a child with SCD?

Se wo ye agya a w' abofra wɔ SCD ahotutuo yareɛ bi yi no , so adwene a wo wɔ fa abofra yi ho no gyina nea amanfoɔ ekeka no so anaa?

Managing SCD as a Social Construct

29. In what traditional ways does society manage SCD? How helpful are these to the patient and family?

Kwan ben so na efie foɔ fa so eko SCD yareɛ no?

30. What restrictions if any does society place on the life style of the SCD child? Why and what are the effects? What can the father do?

So neemma ben saa na eyaa efie foo empene se SCD ni ebeye anaa obedi? Eho nsunsuan soɔ ne den? Edeen na Agya no betumi aye wɔ saa adeɛ no ho?

Social Meaning of Fathering a child with SCD

31. Tell me the story of your typical day now as a father of a child with SCD.

Yenfa no se homeda bi a wo ankɔ baabiara no, edeen na wo ne wo ba yi eye da mu no nyinaa?

32. Tell me the story of your typical day when the child is ill.

Yenfa no se da bi a abofra yi yare no nso edeen na wo ye da mu no nyinaa?

33. Tell me the story of your typical day when you are with this child gets better?

Yenfa no se da bi a abofra yi eho ye nsoeɛ edeen na wo ne no ye da mu no nyinaa?

34. What makes some men bring their children to hospital themselves whilst others do not?

Edeε na εma Agya nom bi etumi de womma ba dokota na ebinom nso entumi?

35. What role does traditional division of labour play in this practice?

So amammere nhyehyeye a εwo mmaa ne mmaama ntem no na ema no ba saa no anaa?

36. Is it important to increase paternal involvement in hospital care of their SCD children? Explain? How did some overcome it? What can be done to?

So eho hia se yebema agya nom enya aho keka bi wo saa mma yi ho dokota kɔ mu anaa?

37. Tell me about your child(ren) with SCD (schooling, age, what like best, relationship, dreams sharing etc.)

Ka wo ba (mma) a ɔwɔ SCD ahotutuo yare yi ho asem kakra kyere me (ne sukuu kε, ne neyɔye mu, ene ɔne nuanom asetena mu etc.)

38. What are your feelings now that you have had the opportunity to share in the life of this child?

Sesee yi a wo ne abofra yi atena na wo ne no enya ayonkofa bi yi, nsusuyε ben na wo wɔ εfa ɔno ene yareε yi ho?

39. Are your feelings for this child any different from that of the other children? Explain.

So nsonsonoye bi da w'adwene a wo wɔ εfa wo ba a ɔwɔ SCD ahotutuo yare yi ho

40. What has been your worst experience with SCD? Explain. What did you do?

ene ne nua nom mu anaa? Kyere asee.

41. What has been your best experience with SCD? Explain.

Edeεn na ekaε wo anigyεε wɔ SCD yareε yi ho?

42. Why do some fathers abscond from their families/child? What can be done to keep these men interested in their child?

Edeen na ema agya nom bi etwe won ho fi mma a ewo saa yaree yi bi ene won maame ho? Eden na ebetumi aye na saa adee yi agyae?

Family Perceptions and Marital Relationships

43. Tell me the relationship that exists between your other children and this child with SCD (rivalry, preferential treatment etc.). Explain.

Ayɔnko fa ben na eda wo mma a wonni yaree yi bi ene wommo nua no a ɔwɔ bi no ntam?

44. What is the whole family's (nuclear and extended) perception of SCD and this SCD child?

Edeen nsusuye na abusuadom no ewɔ fa yaree yi ene abofra yi ho?

45. Has the birth of this child affected your marriage or married life in anyway? Explain.

So abofra yi awoɔ aha w'awaree anaa w'aresem wɔ kwan bi so anaa?

Coping and Support Systems

46. Tell me about the support you receive from family, friends and organisations or societies to enable you care for this child. What does each do?

Mmoa ben na wo nya firi w'abusua mu, nnamfoɔ nkyen anaa se akuokuo mu a eboa wo ma wotumi hwe akwadaa yi ? Edeen na wommo ye?

47. Has this help been instrumental in helping you cope with SCD? Explain.

Egyina saa mmoa yi so na etumi ama wo ne yaree yi atentam anaa?

48. In what way can society (family, friends and organisations or societies etc.) help to make parenting a child with SCD any better?

Kwan ben so na wogyedi se abusua,, nnamfoɔ, anaa se akuokuo betumi aboa ma abaatanyɔ wɔ yaree yi ho aye yie?

49. What role has your religious belief played in your courtship (testing of blood), marriage, childbearing and in caring for this SCD child? Explain.

Eden na wogyedie a wogyina mu eyeeye efa wo ne wohokafo ɔ nnamfo fa mu efa SCD yaree yi ho ansa na mo ware? Mo awaree muee? Awo ɔ mu ene abofra yi hwe mu nsoee?

50. How widespread is the practice of churches requesting testing of blood before marriage? What role can this practice play in social development?

So nsorensore a ewo nhyehyeye se awarefo ɔ biara bewhewhe won mogya mu ansa na aware no abaso no , ede mpontu de ba anaa?

51. Tell me what you think religious affiliations could do to help such parents as their members.

Edeen na w'adwene ye wo se mmofra a w ɔmmo w ɔ SCD yaree yi awofo ɔ gyidie a w ɔmmo gyina mu anaa w ɔmmo asore a w ɔmmo k ɔ ebetumi aye aboa w ɔn w ɔ abofra yi hwe mu?

52. What kind of support has been available to you through the health sector? Gov't?

Edeen mmoa na wanya firi apommuden asoye anaa aban ho na etumi aboa woahwe abofra a ɔw ɔ SCD yaree yi?

53. Is there anyway that you think the health service could better care for children with SCD? What can they do for a father like you?

Ekwan ben so na w'adwene ye wo se apomuden asoeye ene aban betumi ahwe mmofra a wommo w ɔ SCD yaree yi bi?

Other

54. Is there anything else you will like to add?

Nkommo a yab ɔ yi nyinaa so biibi wo h ɔ a wo be pe se wo be ka aka ho anaa?

55. Is there any question you will like to ask me?

Asem bi wo h ɔ a wo be pe se wo be bisa me anaa?

Conclusion (Awieε)

- . What made you agree to do the interview?

Edeεn na εmaa wo gye too mu se wo ne me ebedi nkommɔ yi?

- . How did you feel taking part in this interview?

W'ani gye se me ne wo dii saa nkommɔ yi anaa?

- . Is there anything that I would have done that would have disallowed me from interviewing you?

So biibi wo hɔ a anka me yεεyε a anka ebetumi esi ho kwan ama worempene se me ne wo be di saa nkommɔ yi anaa

- . Are you still happy for me to use this information as earlier stated?

Wo pene so bio se nsem a wo kayerε me wɔ nkommɔ yi mu no memfa nyε adwuma anaa?

Appendix II Information Sheet about the Study

NOTE: The information was translated into local language (Asante Twi) and verbally explained to them.

STUDY TITLE: The social Meanings of a Child with Sickle Cell Disease: The reaction of and social-psychological impact on fathers.

Dear Sir/Madam,

I am carrying out the above research study through the Sickle Cell Disease Association – Ashanti. I was referred to you through Mr./Mrs./Ms.....

I wish to request your kind participation in the study. To help you understand what the study is about, please carefully read the information below.

Should you desire more information concerning this study to help you decide, do not hesitate to contact me through the contact below. You can keep this information sheet but will have to return the signed consent form. Thanks very much.

WHAT IS THE STUDY ABOUT?

In our social context, care of chronically ill children have commonly been the responsibility of mothers though in the background fathers provided both logistical and emotional support to their families. Studies carried out in the past indicate that mothers are the ones often seen at the direct bedside of the child and appear to be dealing with most of the problems that arise. Little information however if any exist to describe the meaning fathers give to similar situations and the way they cope with their feelings. The availability of such information by taking part in this study, will help to provide another side of how families cope with chronic illness and the social provisions that need to be in place to support families such as yours in living with the disease.

WHY DID I HAVE CONTACT YOU?

I am conducting this research in Kumasi and my main contact has been through those who attend the Sickle Cell Association monthly meetings at Okomfo Anokye Teaching Hospital. Apart from you I will be talking to other fathers I have been referred to through the mothers/wives who attend this meeting.

WHO IS INVOLVED IN THIS STUDY?

The main person involved in this study is myself as the researcher. However I have sought permission to carry out this study from the Ministry of Health / Ghana Health Service, Okomfo Anokye Teaching Hospital, the Association and the Sickle Cell Project in Kumasi. However, I have some very senior colleagues in England who will be supervising my work to ensure that adhere to ethical guidelines.

IS IT COMPULSORY FOR YOU TO BE INVOLVED?

Not necessarily. You are obliged to decide not to be interviewed. It is entirely voluntary and will in no way affect my or the hospital's relationship with you, your wife/partner and the child. If you agree to take part, you will be required then to sign a consent form.

WHAT FORM WILL THE INVOLVEMENT TAKE?

Based on your consent to take part, I will arrange a time and place suitable and appropriate to us both and we will have a discussion on the topic stated above. This will require about 30 minutes to one hour of your time.

WHAT WILL HAPPEN TO THE INFORMATION?

Rest assured that everything you say will be confidential. Your name will not be recorded during the discussion. I will assign a different name to you so that nobody will even recognise that the information is coming from you.

As the researcher, I will go back to the privacy of my room after the meeting, play the recorded discussions and write them all out and labelled using the different name I have given to you. All information will be safely locked in a drawer. If you so desire, I will play back our discussions to you after the interview so you can listen and confirm your contributions. When the research has been fully completed and I do not need the information again, the recordings will be erased. All data will be handled according to the current Data Protection Act (DPA) Note: (Will replace with similar one for Ghana if exists).

IN CASE YOU HAVE COMPLAINS TO MAKE

If you have any questions or complains to make concerning anything related to this study, please feel free to talk to me about it or you can call me on Te. No. 020-8171282. My address for physical contact is:

C/o The Project Office, Newborn Screening for Sickle Cell Disease in Ghana
Okomfo Anokye Teaching Hospital
Kumasi

OR

C/o The Kumasi Health Education Unit
Kumasi Metropolitan Assembly
Adum, Kumasi

WHAT HAPPENS TO THE FINDINGS OF THIS STUDY?

When the study is completed, I will compile a report of the findings to be submitted to my senior colleagues in England as part of an academic requirement. No respondent name will be included in the report.

IS THERE ANYONE FUNDING THIS STUDY?

No, there is no one. I am carrying out this study as an academic exercise.

Contact for further information

Please do not hesitate in contacting me if you require any information. My contacts are
Tel. No. 020-8171282

My address for physical contact is:

C/o The Project Office, Newborn Screening for Sickle Cell Disease in Ghana
Okomfo Anokye Teaching Hospital, Kumasi

OR

C/o the Kumasi Health Education Unit,
Kumasi Metropolitan Assembly
Adum, Kumasi

Thank you very much for taking time to read this sheet

Signed: Mrs. Jemima Araba Dennis-Antwi

Date:.....

Appendix III**Ethical Application*****THE CHAIRMAN*****COMMITTEE ON HUMAN RESEARCH, PUBLICATIONS AND ETHICS,
SCHOOL OF MEDICAL SCIENCES, UNIVERSITY OF SCIENCE &
TECHNOLOGY, KUMASI**

Dear Sir,

I am presently a **research student (PhD)** studying at the School of Health and Applied Social Sciences, De Montfort University, Leicester, England. As part of my academic work, I am carrying out a study into the *“The Social Meanings of a Child with Sickle Cell Disease: The reaction of, and social-psychological impact on fathers”*.

As you may be aware, I was part of the Newborn Screening for Sickle Cell Project in Ghana for about 10 years (1993-2003) and over the period developed an interest in finding out more about fathers of chronically ill children.

In this study, I wish to interview fathers of children with sickle cell disease. I hope to be able to gain access to the fathers possibly through the Association meetings held in Okomfo Anokye Teaching Hospital monthly.

I shall be grateful for your kind permission in allowing me to conduct this study.

If you wish to confirm my status please contact my supervisor **Dr Simon Dyson** through the address below:

Unit for the Social Study of Thalassaemia and Sickle Cell
(TASC Unit) [<http://www.tascunit.com>]
School of Health and Applied Social Sciences
De Montfort University,
The Gateway,
Leicester
LE1 9BH
United Kingdom
+ 44 (0) 116 257 7751 (Direct Line)
+ 44 (0) 116 257 7700
sdyson@dmu.ac.uk

Counting on your cooperation

Yours Sincerely,

JEMIMA ARABA DENNIS-ANTWI
Research Student

**COMMITTEE ON HUMAN RESEARCH, PUBLICATIONS AND ETHICS,
SCHOOL OF MEDICAL SCIENCES, UNIVERSITY OF SCIENCE &
TECHNOLOGY, KUMASI**

PRINCIPAL INVESTIGATOR (Ghanaian)

NAME AND DEGREES JEMIMA ARABA DENNIS-ANTWI,
MSc HP/HE, BScN, SRN, SCM, PHN

DEPARTMENT: **NATIONAL HEALTH LEARNING MATERIALS
CENTRE, GHANA HEALTH SERVICE, P. O. BOX 1908,
KUMASI.**

Phone: **051-29434 OR 30367**

IS PRINCIPAL INVESTIGATOR ADVISOR ONLY? **NO (active- AS A REQUIREMENT TOWARDS
THE AWARD OF A PhD DEGREE)**

CO INVESTIGATOR :

NAME AND DEGREES: **Dr Simon Dyson**

UNIVERSITY TITLE: **Reader in Applied Social Sciences**

DEPARTMENT: **Unit for the Social Study of Thalassaemia and Sickle Cell
(TASC Unit) [<http://www.tascunit.com>]
School of Health and Applied Social Sciences
De Montfort University,**

**The Gateway,
Leicester
LE1 9BH
United Kingdom
+ 44 (0) 116 257 7751 (Direct Line)
+ 44 (0) 116 257 7700
sdyson@dmu.ac.uk**

GHANAIAN/FOREIGNER? **FOREIGNER**

TITLE OF PROPOSAL:

***The Social Meanings of a Child with Sickle Cell Disease: The reaction of, and social-
psychological impact on fathers.***

Appendix III cont'd ADMINISTRATIVE REVIEW FORM TO CLAIM EXEMPT STATUS.

Investigator's Name : JEMIMA ARABA DENNIS-ANTWI

Dept : c/o NATIONAL HEALTH LEARNING MATERIALS
CENTRE / NEWBORN SCREENING FOR SICKLE CELL
DISEASE IN GHANA, KUMASI

Mailing Address: NATIONAL HEALTH LEARNING MATERIALS
CENTRE, GHANA HEALTH SERVICE, P. O. BOX 1908,
KUMASI.

Fax: Phone: 051-29434 OR 30367 Date: 1ST JANUARY 2004

Study Title:

The Social Meanings of a Child with Sickle Cell Disease: The reaction of, and social-psychological impact on fathers.

Principal Investigator's Signature:

1. Give a brief description of this study

Sickle cell disease is a debilitating chronic illness that brings considerable hardship to patients and families affected by the disease. Its psychosocial aspects have been studied in the developed world with respect to ethnicity, low income groups (Hill, 1994), coping strategies among carers especially mothers (Midence and Elander, 1994) and how it had to be politicised in order to derive attention from the powers that be within developed countries (Anionwu and Atkin, 2001). In Ghana itself, the clinical course of sickle cell disease has been studied (Konotey-Ahulu, 1991) but little work has been conducted into the social and psychological implications for the families affected, nor into how sickle cell is socially constructed (Burr, 1995) by the families as they learn to live with the disease. Studies have shown that managing a chronically ill patient affects the physical and mental health of the mother especially (Shapiro et al, 1987). Little however, has been

documented about fathers' role in sickle cell disease management and how they also cope with having such children, possibly because to date most of the groups studied have had to raise these children as mothers alone without fathers (Hill, 1994).

In some cases the presence of sickle cell children has led to fathers withdrawing from the family, to separation or to divorce. Public reasons most commonly ascribed to the behaviour of such fathers have been that they are irresponsible. Some of the social and cultural features associated with black families might be expected to assist them in accommodating chronic illness whereas others may militate against successful adaptation (Le Pontois, 1975). Until more is known or acknowledged about the way that socio-cultural and psychological factors affect family(fathers) adaptation to chronic illness, the scope for improvements in the provision of effective psychological and social support services towards such families will be significantly restricted.

Aims of Research

- *To investigate and describe the social and cultural meanings of sickle cell to fathers of sickle cell disease (SCD).*
- *To understand and describe the feelings, motives and behaviour of Ghanaian fathers of children with SCD.*
- *To make recommendations for social policy for SCD management in Ghana.*

Methods

An attempt to study the social meanings a group attach to a child with a chronic disease which has been socially constructed and reconstructed over generations such as SCD calls for methods that allow for close interactions with the group being studied rather than the reliance on observable factual phenomena from a positivist standpoint. Positivist methods such as surveys will generate data describing the magnitude of the problem and possibly reasons for certain actions, but will not be able to capture the meanings and values the group give to their particular actions. According to Pawson (1989) problems with imposition and correspondence cannot be ruled out in such studies and will therefore affect what exactly is being measured.

To counteract these problems and to achieve the purpose of this study, a qualitative framework of data collection will be employed that entails a triangulation of methods (Bryman, 2001), including in-depth interviews (and re-interviewing), focus group discussions (FGDs) and a reflexive fieldwork diary to ensure a higher degree of confidence in findings. It will also provide a higher response rate than surveys due to personal interactions of the methods. Cognisance is taken of the documented limitations associated with these methods such as likelihood of losing control over proceedings of FGDs, heavy reliance of interviews on verbal behaviour and problems with transcribing interviews. Practical steps will be taken to limit these disadvantages through good note taking and use of skills in group facilitation.

Interviews will be conducted using a previously tested topic guide (in appendix). This topic guide will be developed through the review of literature, advice from supervisors,

senior professional colleagues and families living with SCD. The local language of 'Twi' which is widely spoken will be used as the medium of communication. The researcher is very fluent in this language and will therefore not require the mediation of a translator.

To ensure all respondents are comfortable with the research, there will be a general seeking of consent before each interview. The consent form (see appendix) will be verbally translated into 'Twi' and communicated to them. Respondents consent will be tape-recorded for reference rather than signed. This is to ensure a consistent method of seeking consent as it is likely that not all respondents may be able to write.

The necessary arrangements will be made to determine where and when if appropriate, the fathers who have consented to be interviewed desire to meet the researcher. At the end of the interview, respondents will be asked to confirm by speaking their consent on the record at the end of the taped interview, confirming if they are still happy for the researcher to use the information that has been obtained.

All verbal communications will be tape recorded in order to provide a record of actual occurrences in their actual sequence as Sacks, (1984) puts it, labelled using a predetermined pseudonym and stored safely. Full transcription of the interviews will be carried out in English by the researcher. Field notes will be kept by the researcher to enrich the data collected to assist in data analysis.

Ethical Issues

To address these potential ethical problems of intrusion of privacy, the researcher intends conducting a focus group discussion with mothers of SCD children who will assist among others in helping to gain informed consent from their husbands or partners to be interviewed.

They will also be assured as part of the information sheet read to them that they have the liberty to refuse to be interviewed and that it will not in anyway affect their relationship. They will also have the liberty to refuse to answer questions that they do not feel comfortable answering.

On the subject of reliability, the researcher will strive for reflexivity by means of a research diary and construct an 'audit trail' documenting the processes of research in order to enhance the transferability of findings to other contexts.

Validity will be achieved partly by permitting the fathers to speak freely within their own frame of reference without imposing the researcher's own framework onto their social world. Furthermore, it is anticipated that the triangulation of methods of data collection involving FGDs, in-depth interviews and fieldwork diary will also enhance the validity of the data.

Analysis

The methods to be used in this research will lead to the generation of large volumes of unstructured text. It is generally known that there are no straightforward rules that guide the analysis of qualitative data when compared with quantitative data (Bryman, 2001:387). However, there are approaches that could be employed. Analysis of this research data will involve the identification of patterns, processes, common ideas and differences (Miles and Huberman, 1994) that may emerge from the transcribed text and the use of these as a basis for generating themes or interconnections relevant to the categories of data at hand.

2. Which exempt category does this research fall within?

Category 9 (Research on individual or group behaviour or characteristics of individuals such as studies of perception, cognition, game theory, or test development, where the investigator does not manipulate subject's behaviour and the research will not involve stress to subjects).

3. Will any subjects be contacted for purposes of the study?

YES

If so, describe the contact process:

The sample will comprise up to 50 self selected or recommended fathers. The self selection method will be similar to that used in a study by Lupton et al (1995). In her study, participants were recruited by a poster pasted at selected clinics. In this present research, fathers will be recruited through self nomination, their wives or partners who are members of a support group closely affiliated to a project screening babies at birth for SCD in Ghana. The Newborn Screening for Sickle Cell Disease (SCD) Programme in Ghana is an international collaborative research project, which was started ten years ago in Kumasi. The investigator of this study has been a part of this project for the past ten years as its Education and Counselling Coordinator until recently. This sampling strategy may mean those who are less integrated into local support groups, and those where the mothers do not give permission to approach the father will not be represented in the sample. However, the proposed methods of approach seem the only ones possible to generate a sample of fathers of children with SCD.

Permission will be sought from the

- ❑ Faculty Human Research Ethics Committee of De Montfort University to meet an academic requirement and to convince the Board that ethical issues will be acceptably addressed in the research.
- ❑ Committee On Human Research, Publications And Ethics, University Of Science And Technology, School Of Medical Sciences, Kumasi
- ❑ The Advisory Committee of the Newborn Screening for SCD Programme in Ghana through the Co-Investigator of the Project

- ❑ Ghana Health Service/Ministry of Health through the Regional Directorate of the Ghana health Service in Ashanti.
- ❑ Sickle Cell Disease Association of Ghana-Ashanti Region Branch through the President of the Association for onward submission to the executive board for their approval.

4. Will subjects be completely anonymous? Who will have access to study data?

NO. But the data collected will be anonymous to any other apart from Principal Investigator and Research Degree Supervisor.

If not, how will their identities be coded? How long and in what way will records be retained?

All information collected during the research will be treated as highly confidential. All field notes and tapes will be kept under strict lock and key until the successful completion of the research degree. The transcription of the recordings will be done in the privacy of a room where if possible only the researcher has access to.

A list of all respondents will be made separately before interviews and transcriptions begin and a pseudonym will be given to each one of them. This pseudonym will be used for all labelling and references whilst the master list is kept separately and private. Respondents will be assured of this and copies of labelling shown to them.

5. Will there be any data collection sheets used for study purposes? No Yes If so, please submit one copy of each.

YES. An interview guide will be used. (see appendix)

Certificate of Exempt status

On the Basis of the information presented here this research activity qualifies as exempt from review by the CHRPE

Chairman, Committee on Human Research, Publication and Ethics

Denial of Exempt status

On the Basis of the information presented here this study does not qualify for exempt status and an application written in accordance to the CHRPE guidelines should be submitted to the Committee on Human Research, Publication and Ethics, UST, SMS, Kumasi.

Initial Short Form Review: Full Committee review

Chairman, Committee on Human Research, Publication and Ethics

Appendix V Field Diary for Each Respondent

(Fill in just before interview and immediately after) *Date:*

Place of interview and Why Choice:

Time Start:

Time Finish:

Socio-demographic Details

Name & Address (will not be recorded on to tape)

Tel Number if any (will not be recorded on to tape)

Age

Number of Children/sex/number with SCD/ Age of SCD child (ren)

Marital Status: (Single, married, separated, divorced, widowed)

If divorced, has he re-married?

Number of Wives

Religion

Occupation

Where your parents live

Ethnicity

Observations by researcher if interview is held in house

Living with children

Own a car

Type of housing

Surroundings

Willingness to Participate

Extreme

Agreed upon

Extremely

Reluctance

Asking

Enthusiastic

How Respondent was accessed:

Sampling Basis (Self Select/Gate keeping/Theoretical Sampling for diversity):

If theoretical sampling, state for which diversity:

Comments about outcome of Interview/Observations made on respondent's willingness to talk about questions, expressions, mannerisms, mood etc.

Appendix VI Example of Documenting the Process of Analysis

Knowledge and Meaning of SCD

PHRASES/STATEMENTS	SOURCE OF REFERENCE	CONCEPTS	THEORETICAL CONSTRUCTS
		Knowledge and Meaning of SCD	IMPACT OF SCD
Tell me about what you knew about sickle cell disease (SCD) before you 2 got married. I had heard of the disease. I remember a brother's son used to have swollen feet of and on . Unfortunately that child died so we were all filled with	F2 Pg 8		
Before I had this child with my partner, I had heard that 2 people with AS could produce a child with SCD.	F3 pg 14		
We knew nothing at all when we had our 1 st child who has SCD. By the time we had our 4 th child also with SCD, we had then heard about the disease and seen its manifestations but we still had no education about the disease. <i>Int: Were you aware you could have more children with SCD, having had one already?</i> No! It was not until the Newborn Screening Programme started in Kumasi and we had opportunity to attend some of the education sessions that we began to understand what this disease is all about. It was during that period that I had the 4 th child	F4 pg 21	Knowledge and Meaning of SCD	IMPACT OF SCD
Tell me what you knew about SCD before you 2 had your child(ren) with SCD. No. I did not know anything about it though I had heard of it. It is my 3 rd child who has SCD. The first two do not have it.	F2 Pg 8		
Before I had this child with my partner, I had heard that 2 people with AS could produce a child with SCD.	F3 pg 14		
We knew nothing at all when we had our 1 st child who has SCD. By the time we had our 4 th child also with SCD, we had then heard about the disease and seen its manifestations but we still had no education about the disease.	F4 pg 21		

<p>Would your previous knowledge about SCD have made any difference in your decision to marry? Explain.</p> <p>In that situation you are not married yet so it is easy to make a decision but when you have married the person and had 3 issues with the 3rd having disease, it becomes a different matter. Children are given by God so if he has given we've got to take it.</p>	<p>F2 Pg 8</p>	<p>Knowledge and Meaning of SCD</p>	<p>IMPACT OF SCD</p>
<p>I was sad when I got to know my child had SCD. I am still in a relationship with the mother because the doctor told me that though it is lawful for me to decide to break the relationship, the time is not ripe.</p> <p>If I knew that my partner and I were both AS, I would have stayed in the relationship to produce a child.</p> <p>gotten over it. For you to bring a child into the world for the child to suffer for the rest of his life is not the best thing to do.</p>	<p>F3 pg 15</p>	<p>Knowledge and Meaning of SCD</p>	<p>IMPACT OF SCD</p>

<p><i>What prevented you from checking your blood? Did you know you could? Does it mean that you do not intend to marry her?</i></p> <p>In fact I knew we could check but unfortunately it did not occur to me.</p> <p>Well if I am sure our subsequent children would not have the disease then I could reconsider my decision. This is because taking care of such children is expensive and it seems that there is always this feeling of sadness about the child because of the sickness. It is also a time consuming illness. Supposing you need to go to work and the child is ill. You cannot leave him. You will need to take him to the hospital. So as for me having a child with SCD has really been a painful experience. I have still not</p>	<p>F3 pg 15</p>		
<p>Truthfully, if I had known what I know about SCD now back then when I met my wife, I think we would not have married. We would have come to an understanding and parted our own ways. But because we did not have that opportunity, we entered marriage which is for eternity. When you enter marriage, there is no going back.</p>	<p>F4 pg 21</p>		
<p>Would your previous knowledge about SCD have made any difference in your decision to have a child? Explain.</p> <p>Definitely we would have children</p>	<p>F2 pg 3</p>		

<p>Yes it would have. In the first place, children are important. In this world, your children could even immortalize your name if you were not able to achieve much in your lifetime. So they are important. Though I may love the woman, a previous knowledge would have prevented us in the first place from having this child. I would definitely have terminated the relationship before it led to a pregnancy</p>	<p>F3 pg 15</p>	<p>Knowledge and Meaning of SCD</p>	<p>IMPACT OF SCD</p>
<p>Hmm (laugh)! As I have indicated, I love the woman so I don't see why I would not have a child with her. Children are God's blessing to marriage. If I knew we could have an SCD and I went ahead to marry her then its outcome of a child must be considered a blessing, unless God does not give us a child.</p>	<p>F4 pg 21</p>		
<p>Tell me all that you know about SCD (definition, signs and symptoms, treatment and home maintenance).</p> <p>Its characterised by fever and pain in the joints. In such situation I have to do my best to relieve her of this distress</p>	<p>F2 Pg 8</p>		
<p>I was sad when I got to know my child had SCD. I am still in a relationship with the mother because the doctor told me that though it is lawful for me to decide to break the relationship, the time is not ripe.</p>	<p>F3 PG 14</p>		
<p>I have not had much knowledge apart from the AS issue. When we met Dr X, our discussions centred on the child and he encouraged me not to give up on the child but rather we should see how best to bring up the child. So I really have not had much education. The mistake I made is that we did not check our blood before having this child. I love my partner and would have loved to marry her but what I want to know is whether it is possible for us to know if our subsequent children will not have the disease.</p> <p><i>That is a question to me right? At the end of our discussion, I will try to answer and explain.</i></p>	<p>F3 pg 15</p>		

<p>What I have learnt is that it is a familial disease inherited through ones parents (both of them). The bearing of an SCD child is wrought with many trials and suffering. You will go through so many harrowing experiences that if you don't have a regular source of income you will be devastated and discouraged. But that is the child you have received as a father so you have to do your possible best for the child. Learning about the disease has helped me develop a positive attitude. It challenged me to test my blood and that of my wife to confirm that we were traits. This has even led me to take up an ambassadorial role to share the knowledge I have gained with the youth in my village. I urge them to check their blood before marrying. I have some joy in being able to do this. This is why I am so active in the Association work. I have been able to identify a number of children in my village and brought them to the SCC.</p> <p>As a father you will go through a lot but it is better not to dwell on that but rather be willing to help.</p>	<p>F4 pg 22</p>		
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Knowledge and Meaning of SCD			
PHRASES/STATEMENTS	SOURCE OF REFERENCE	CONCEPTS	THEORETICAL CONSTRUCTS
		Knowledge and Meaning of SCD	IMPACT OF SCD
9. Tell me what you knew about sickle cell disease (SCD) before you 2 got married.			
F8	Honestly I knew nothing about the disease. I had heard of the disease but I did not care much about it or pay any attention to it.		

F9	<p>Yes as I earlier indicated. I knew I was AS so we checked my wife's and this was in London. We were cocksure she was AA. So having a child with SCD is a real shock to us. We did check and were damn sure. The thalassaemia thing is new to us. I had heard about the disease. My Aunt had lost a child to the disease when we were kids and it was a painful experience for us all so I was particular about avoiding it. When I saw that my wife was AA, I was pleased. But I remember the doctor told her that when she gets pregnant she should show it to a doctor. And we did. We did not think of SCD until we had the baby and he started showing signs of ill-health.</p> <p><i>Int : I think the problem arose from the diagnosis. Thalassaemia is a bit difficult to diagnose so may be that is where the problem arose. Sometimes even in the developed countries, mistakes arise. SCD had not been one of public health interest even in the developed countries because it affected only the minorities. It is only in the last 20 years that there have been marked improvements in SCD care.</i></p> <p>I have a strong feeling that if our health system could be more responsible in the laboratory investigations they carry out and these investigations are highly accurate that will solve a lot of the health problems we have here. Unfortunately laboratory test are not given the serious attention they deserve. If you go abroad, you will realise that lab investigations are most crucial to diagnosis and care. Lab tests there are very expensive. But if you come here it seems our lab technicians are barely regarded and that is where our problem lies. This problem is not only found in the health sector. Even in the Agric sector minimal research is done to determine causes of problems. The development seen in the developed countries have their foundation in lab work. We have gone to the top instead of dealing with the base. If I take my child for instance when we sent him abroad for surgery, we studied the bills that came in and we realised that the cost was equally spread across all the disciplines (surgeon, anaesthetist and the laboratory component) but here it is not like that. Most of the money goes to the top (doctors). There is the need for understanding. The lab creates the knowledge. Our labs must give the quality results so that proper diagnosis and treatment can be given.</p>
F10	I knew nothing about it though I had heard of it. I did not know that you needed to carry out some test to determine your status.
F11	Yes I knew SCD. I am SC. In the past, I used to have lots of problems with it when I was younger. I had painful crisis from time to time and I would go to the hospital. But as I got older, it seemed to be less of a problem. I was very particular with my drugs and would buy any recommended drug including herbal preparations. So I took these medications for a long time until I felt better. I used to have lots of fever bouts but now I can go a whole year with no problem. It is only when I eat groundnut or okro that I experience some feeling of unwell. So I don't eat them and I have not experienced any pain of recent. This illness is troublesome so I make sure I take my daily dose of folic acid. I have also been told to take lots of water and I do that daily. I was able to predict the onset of illness and would immediately take precautions.

F12	Actually yes! In fact , erm, let me go back to history. With my first wife, we had a child apparently with SCD. We were then in Cape Coast. We used to see symptoms such as swollen feet but we did not know it was SCD. Eventually the child died. His condition was complicated by measles and he died. I was so devastated that though I was quite advanced in age, I did not feel like marrying for a while because I loved my child so much. If I think about that bouncy baby boy, it hurts so much. Subsequently when I married this present wife the child started getting sick and showing symptoms similar to the first child who died. He was even admitted to hospital about twice. He was born in a private maternity home so he was not screened at birth. It was during his third bout of illness that the doctor at the hospital requested for lab investigations. It came out that he was SS. That prompted me and my wife to check ours too and we were both AS.
F13	No I knew nothing about it.
F14	No I knew nothing
F15	In Sierra Leone I had heard that it is a disease that brought lots of pain to the patient and there is usually lack of good health.
F16	Yes I had heard of it. I had a friend in the US who was sending me pamphlets on some disease conditions of which SCD was one. <i>Why was he sending you the literature?</i> Because that was what he was studying. I was particularly interested in SCD because I had a nephew who showed symptoms similar to what was described in the literature. He was my sister's first born and I loved him so much. Unfortunately the boy died. Then I did not know it was SCD. So several years later, It was only when I read the literature that it dawned on me that the child was suffering from SCD. I remember he used to take all sorts of drugs. That time they always said he had 'ahotutuo' as we locally call the disease which worsened during cold weather. He always had yellow eyes. I loved him so much.
F17	No I knew nothing about it though I had seen someone with episodic pain 'ahotutuo', I did not understand the cause of the disease or what it meant.
F18	Yes. I had a senior sister I lived with right from infancy who had an SCD child. When he is ill in the night, we used to rush him to the hospital so I had a little knowledge about the disease. Now she is a big girl. She has completed SS and is doing well.
F19	I had heard of 'ahututuo' but not in the sense of it being a blood related disease.
F20	I had heard of the disease but I did not know of its implications or its associated problems until I had a child.
F21	No I had never heard of sickle cell disease. I had heard of rheumatism but not this one.
F22	I knew someone with the disease and how he used to writhe in pain but I did not know how he came by the disease. So I would say I knew nothing about it.
F23	Oh no I did not know about it until I had this child. I had heard of the disease but not seen one.
F24	Before marriage, yes I had heard about SCD but did not know what it was or what it meant and its implications for marriage.
F25	No I knew nothing about it. It was later that I heard about it on radio.
F26	Yes I had heard about it and seen s.o with it before. When we were in school, we had a colleague who had it and during cold weather he develops serious pains and he had to be tied up. Sometimes too they say he needs blood transfusion. So yes I knew about it before meeting the mother of my child
F27	Yes I had heard of SCD. That when the couple's blood are incompatible with each other that is when you have such children. I have also heard that you could have some or all the children having the disease. I have seen a few people with the disease.
F28	Yes I knew about it but I did not think that SCD could do what it has done to my little daughter in the last 2 months. Now when I see my daughter I am filled with sadness and pity for the poor girl
F29	Oh! I k new about SCD. I knew that if one is in your family you will spend a lot of money buying drugs. That there will be times the child will be in pain and will be crying a lot. That the child will go through a lot of challenges. I knew all these because our elders used to talk about it and referred to it as 'ahotutuo', we used to see people with it at school. In the boarding school we OFTEN made fun of them because we did not know much about it as it is known today. But as I grew up and got more exposed as well as having the opportunity to work in a laboratory, I began knowing and understanding the disease.

F30	<p>Yes I knew something. Before we went into training college, we had the belief that SCD was caused by evil spirits. But in school we learnt about chromosomes and SCD and that it is through parents that children get the disease. But we did not check our blood before marriage. Now I think that it is best for 2 people desirous of courting to check their blood before getting committed to each other. If this is not done and love takes control, objective reasoning becomes difficult. Even if you are told the person has AIDS you will still go along and marry. SCD is linked to parents and children if anything must blame their parents for bringing them forth with it.</p>
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